

NTID RESEARCH BULLETIN

Department of Research and Teacher Education · National Technical Institute for the Deaf · Rochester Institute of Technology

Vol.12 No.1 Winter, 2009



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National Center for Deaf Health Research

By Vincent J. Samar, Steven Barnett, and Jessica Cuculick

The Rochester Prevention Research Center — National Center for Deaf Health Research (NCDHR) is one of 33 Prevention Research Centers funded by the Centers for Disease Control and Prevention. It was established in 2004 at the University of Rochester to facilitate health promotion and disease prevention with Deaf people and their families. NCDHR is grounded in principles of community-based participatory research (CBPR), engaging researchers and Deaf community members in an equitable research partnership to study and address community health needs in culturally sensitive ways.

CBPR recognizes the unique strengths that all partners bring to a common agenda for research, health promotion, and the elimination of health disparities (Minkler, Blackwell, Thompson, & Tamir, 2003). Under the auspices of NCDHR, Deaf and hearing researchers from the University of Rochester (UR) and the National Technical Institute for the Deaf (NTID) have collaborated with Deaf community leaders to develop a linguistically accessible and culturally appropriate health survey instrument for the Deaf community, to collect essential data that define the health risks and needs of the community, and to develop and undertake community-based health intervention programs.

Organization of NCDHR

The organizational structure of NCDHR (Figure 1) reflects its CBPR philosophy. The Core Research

Project Team, comprised of Deaf and hearing researchers from UR and NTID, develops research methodologies, conducts research projects, disseminates research findings, and implements accessible intervention programs. Other teams support essential NCDHR functions, including communication with various communities and stakeholders, administration, training, and evaluation. Leaders from the Deaf community form the Deaf Health Community Committee (DHCC), which represents the Deaf community and collaborates closely with the NCDHR Program Directorate, the Executive Committee, and subsidiary teams to plan and conduct the NCDHR agenda. Other Deaf community members, professionals who work with Deaf people, and clinical experts monitor and influence core NCDHR activities through their participation on various advisory groups, which communicate directly with the Program Directorate and subsidiary committees and teams.

The Need for Deaf Health Research

National, state, and local programs for health promotion and disease prevention for the general population are developed using critical information from health surveys such as the Behavioral Risk Factor Surveillance System (BRFSS), the Youth Risk Behavior Survey (YRBS) and the American College Health Association - National College Health Assessment (ACHA-NCHA). Survey results are generally used to determine priority health issues, to devise prevention and intervention measures and monitor their effectiveness, to justify public health policy, and to educate policy makers,

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Notes of Note

Fifty leaders in the field of support service provision for postsecondary deaf students in science, technology, engineering, and mathematics (STEM) programs met at RIT on June 25-27, 2008 to discuss the current state of on-line remote interpreting and captioning. One objective of The Summit to Create a Cyber-Community to Advance Deaf and Hard-of-Hearing Individuals in Science, Technology, Engineering, and Mathematics (STEM) was to identify the benefits and challenges of creating a multimedia cyberinfrastructure to

provide these remote services. The summit was led by RIT and the University of Washington and funded by a grant from the National Science Foundation to RIT's **Center for Access Technology (CAT)**. For more information contact **E. William Clymer** at ewcncp@rit.edu.

The **Center for Education Research Partnerships (CERP)** recently began a \$1.65 million grant from

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health professionals, and the general public about health risks and interventions.

Current health surveys are administered over the telephone or through written questionnaires. Because Deaf people usually cannot understand and respond to voiced telephone surveys, they are typically excluded from those surveys. Furthermore, as members of a linguistic minority for whom English may be a second language, Deaf people often find written English surveys with medical terminology difficult to understand and complete accurately. Consequently, valid information about the specific health status of Deaf people, and about health disparities between the Deaf and hearing populations, is not currently available to public health professionals and is not included in program planning. From the point of view of health surveillance and public health policy, then, Deaf people are a seriously underserved and underrepresented community.

To redress this inadequacy, NCDHR developed and fielded the first linguistically accessible and culturally appropriate computer-based health survey with the Deaf community, the Deaf Health Survey (DHS). Health data collected with the DHS is helping researchers, community members, and clinicians to identify and prioritize the Deaf community's specific health needs and to design effective future health promotion efforts to address those needs.

Deaf Health Survey Interface

The DHS asks respondents about a range of health behaviors and risks, as well as basic demographic information. The DHS is administered on a touch screen computer using an interactive interface designed by NCDHR. DHS interface development was guided by an iterative process of evaluation and revision, based on usability studies and extensive cognitive interviews with members of the Deaf community who varied in race/ethnicity, level of education, gender, age, reading ability, vision ability, learning and physical abilities, and language preference. This CBPR process resulted in a highly intuitive interface offering full access to survey content in ASL, signed English, and printed

English, including accessible informed consent, survey instructions, and explanatory materials that overcome fund-of-information gaps for some respondents.

Figure 2 (back cover) illustrates the innovative design and functionality of the core interface item screen. When a respondent presses the *Next* button, a survey item appears (e.g., the basic demographic question "Are you female or male?"). A sign model signs the item's question followed by each of the item's response choices. A key culturally motivated interface feature is the respondent's ability to choose among sign models that differ in race/ethnicity, gender, age, and language modality (ASL or signed English) simply by touching any tab along the left of the signer window any time during the survey. Cognitive interviews with Deaf community members who tested interface prototypes provided formative input on survey item content and confirmed the importance of signer appearance and language choice in determining their comfort with the survey questions and their candor in responding.

The interface item screen incorporates several user-friendly features. Tabs that adjust text size, signer window size, and signer background color facilitate viewing comfort and accommodate respondents with vision acuity and color contrast limitations, such as those with Usher syndrome. Respondents can replay the signer video for any question or response choice before reporting their response simply by touching the text bars that display the question (?) or responses (A, B, ...). Real time captions optionally accompany all signed messages, and a progress bar displays the respondents' progress through the survey. Respondents may return to the previous item and change their response if desired.

Generally, the DHS accommodates many individual respondent needs and preferences. Respondents can initially audition each sign model and select a preferred model to begin administering items. The DHS provides informed consent optionally in ASL or signed English, and simultaneously in print. It automatically orients respondents to the survey content and interface functions using signer guided and graphically animated instructions. It partially compensates



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NTID RESEARCH BULLETIN

The *NTID Research Bulletin* is published irregularly by the Department of Research and Teacher Education, National Technical Institute for the Deaf, a college of Rochester Institute of Technology. It is available without charge. Opinions expressed in the *NTID Research Bulletin* do not reflect those of NTID or RIT. Your comments, questions, and requests for more information are welcome. See following address.

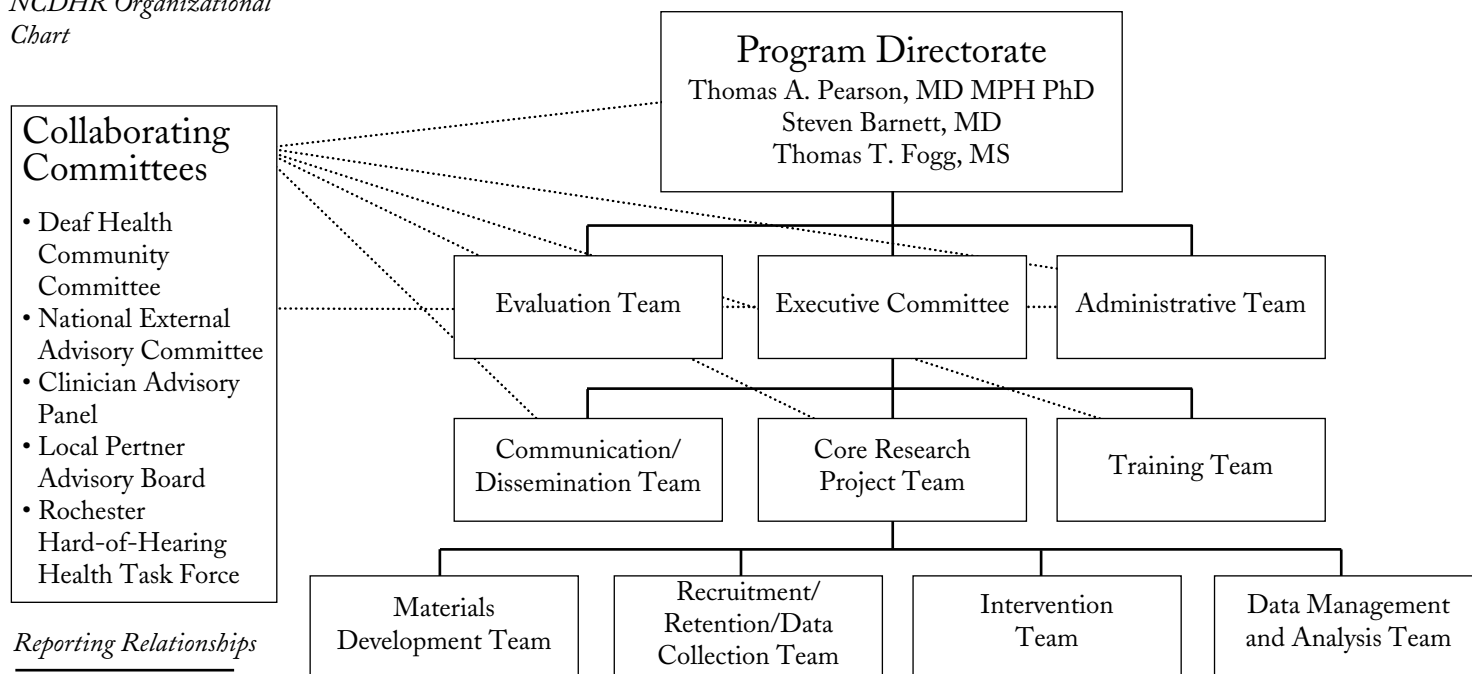
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Figure 1.
NCDHR Organizational
Chart



Reporting Relationships

Communication Lines

for individual differences in respondent background knowledge (fund of information) by providing optional access to a signed dictionary on survey items that contain potentially unfamiliar health terms (e.g., cholesterol). It provides immediate on-screen hotline contact information during the survey when sensitive or potentially disturbing items are presented (e.g., queries about interpersonal violence experiences). And it automatically branches to different items and health themes during the survey based on respondent-supplied information such as gender, age, and health behaviors, thereby avoiding personally inappropriate survey questions and minimizing survey administration time (e.g., male respondents are not shown women's health items).

Survey Content

The DHS contains 98 health related items, including items based on selected items from national health surveys including the BRFS, YRBS, and ACHA-NCHA, and items developed by NCDHR related to deaf population characteristics. Table 1 lists the item categories and topics addressed.

Translation Process

Separate translation working groups (TWG) translated the survey content into ASL and Signed English. All group members were bilingual (ASL and English, or signed English and English), with extensive experience with Deaf culture. Both groups had Deaf and hearing members, including Deaf native ASL users (ASL TWG) and Deaf signed English users (SE TWG).

Four primary operating principles drove the translation process: 1) The expected respondent sample distributions of age, gender, education, geographic region, and familiarity with English vocabulary were considered carefully in decisions about ASL syntax and vocabulary, 2) Translations emphasized meaning equivalence with the English source material, not word-for-word parallelism, 3) To maintain comparability of the DHS results with existing hearing survey norms, translations did not correct inherent ambiguities or logic problems in the original English items, 4) For items that presuppose "common" knowledge, translations included

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the National Institute for Child Health and Human Development to study "Psychological Foundation of Mathematics Performance by Deaf and Hearing Students." The project is a collaboration between CERP and the School of Psychology at the University of Aberdeen, Scotland. For more information contact **Marc Marschark** at marc.marschark@rit.edu

Awareness Month-2008, **Michael Stinson and Justin Mahar, Department of Research and Teacher Education**, demonstrated new C-Print technology at NSF headquarters in Arlington, Virginia on October 30, 2008. NSF is funding development of the new technology by means of the grant, "Remote Speech-to-Text Services for Deaf Undergraduates in STEM Field Settings." Contact Stinson at michael.stinson@rit.edu.

As part of the National Science Foundation's commemoration of National Disability Employment

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Table 1.
Survey item categories and topics

Demographic Items

(e.g., Age, Gender, Zip Code, Current Education Level, etc.)

Health Items

Health Status
Health Care Access
Preventive Services Use
Women's Health
Vision
Diabetes
Blood Pressure and Cholesterol
Cardiovascular Disease
Weight and Weight Control
Tobacco and Alcohol Use
Safety
Sexual Behavior
Interpersonal Violence
Mental Health
Suicide
Learning Disability
ADHD

Deaf Population

Characteristic Items

(e.g., Preferred Language, Parental and Sibling Hearing Status, Level of Hearing Loss, Type of Childhood Schooling, etc.)

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explanatory comments to compensate for expected fund-of-information gaps between the Deaf and hearing populations (Graybill, Aggas, Dean, Demers, Finigan, & Pollard, under review).

Both TWGs encountered translation challenges that stemmed from lexical and structural differences between ASL and English. For example, unlike English, there is no single ASL sign that conveys the generic sense of "suicide". Signs related to terminating one's own life simultaneously incorporate a method (e.g., hanging, shooting, cutting one's wrists). Therefore, translated suicide-related items employed several signs in expanded expressions to achieve a generalized "suicide" concept. Similarly, signed English translations posed ongoing challenges to achieving conceptually accurate and fluent integration of ASL vocabulary, discourse structure, and syntactic features with English word order and other syntactic and production constraints. For example, adverbial phrases that establish time frames in many survey items (e.g., "... during the past 12 months ...") occur optionally at many places in English sentences but usually must occur at the beginning of sentences in ASL. Signed English translations were chosen that respect this ASL discourse property, because they are consistent with English discourse options and are intuitively easier to process for many bilingual Deaf respondents. More generally, translation involved challenges that required attention to linguistic and cultural differences, fund-of-information gaps, and added constraints stemming from the requirement to preserve meaning or to blend two fundamentally different languages fluently and naturally.

The ASL TWG completed an ASL video script of their translations first. The SE TWG worked from this script and the text of the original English items to produce conceptually parallel signed English items and a signed English video script. The ASL and signed English video scripts were back translated by independent ASL/English and signed English/English bilingual consultants, respectively, to ensure accuracy of meaning, and were subsequently revised as necessary. Six sign models (4 native ASL users, 2 fluent signed

English users) recorded the survey materials under professional studio conditions. They varied in age (mid thirties to mid sixties), gender (3 women, 3 men), and race/ethnicity (5 Caucasians, 1 African American). The ASL and signed English video scripts were used to prompt the models in the studio and TWG members monitored their productions to ensure fidelity with the script.

Data Collection and Initial Results

We administered the DHS in Rochester to 302 adults from the Deaf community from February to September 2008. Approximately half took the survey at the NCDHR office, either by appointment or as walk-ins. Others took the survey at community sites, such as the Rochester Recreation Club for the Deaf (RRCD), often during a community event. For a few individuals with limited transportation, NCDHR staff brought the survey to their home. We also administered the DHS to 215 of the more than 700 adults who attended the 40th Anniversary Reunion of NTID in Rochester, June 26-28, 2008.

Table 2 displays basic demographic results for the first 283 adults who took the survey from the Rochester metropolitan statistical area. These demographic data confirm that the initial DHS respondents constitute a diverse sample of the community of people deaf from birth or childhood. The Rochester Deaf community is likely not representative of other US Deaf communities. The Rochester Deaf community is large and well organized with exceptional access to social and community services and health care. Furthermore, this sample tends to under-represent non-white and Hispanic populations and to over-represent the well-educated segment of the Deaf population compared with other American Deaf communities. Therefore, findings from the Rochester DHS will likely underestimate the health burdens experienced by Deaf people nationally.

Dissemination of Results and Future Directions

Researchers and community members are currently working together to analyze and interpret the DHS survey results. Initial survey findings were shared with the broader Rochester Deaf community for discussion and feedback in a series of open town

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Luane Davis Haggerty, Department of Cultural and Creative Studies, published "Adjusting the Margins: A look at leadership literature in the light of Deaf leadership styles" in the November 2007 issue of *JADARA: The Journal for Professionals Networking for Excellence in Service Delivery with Individuals who are Deaf and Hard of Hearing*. In January 2008, she presented "Handamation – ASL Use in the Visual Arts" at the Questfest Conference, in Baltimore, Maryland.

Vincent J. Samar, Department of Research and Teacher Education, received the Buros Institute of Mental Measurements 2008 Distinguished Reviewer Award. The award was presented in recognition of his "long-standing scholarly contributions to the Mental Measurements Yearbook Series."

Table 2.
Basic demographic results
for the first 283 survey
respondents.

Age range	18 - 88
Age mean	46yo
Female	50.4%
Married	48.9%
Hispanic/Latino	2.6%
Race	
White	85.6%
Black/African-American	4.9%
Asian	2.7%
American Indian	1.1%
Other/Multi-racial	5.7%
Education (highest level)	
Some HS	5.3%
HS grad	11.5%
Some college	11.8%
Education (highest level)	
Two-yr degree	22.9%
Four-yr degree	20.6%
Graduate degree	27.9%
Deaf parent or sibling	29.3%
Usher syndrome	2.2%
Education (type attended)	
Only deaf schools	43.5%
Never a deaf school	20.8%
Deaf school & other	35.8%
Age-at-onset of deafness	
Birth	70.2%
< 1 year	9.5%
1 - 7 years	14.9%
Don't know	4.2%

meetings in October, 2008. Together, NCDHR and the broader Deaf community identified obesity and weight control as high priority health concerns for the community. Consequently, NCDHR submitted a renewal application for their Prevention Center grant to immediately implement an intervention program to address these needs. If funded, this program will be based on the existing North Carolina WISEWOMAN: Weight-Wise program (Samuel-Hodge, 2007), which has been proven to be successful with another underserved community. NCDHR will translate intervention materials into ASL and signed English, and will develop, implement, and evaluate a culturally appropriate version of the Weight-Wise program with the Deaf community. Finally, identified health priorities from ongoing analyses of the DHS survey results will be used to support additional grant proposals for Deaf health research in the near future, which will, in turn, promote quality health care for the Deaf community.

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Acknowledgements

NCDHR Core Research Project Team: Steven Barnett, Jessica Cuculick, Tamala David, Robyn Dean, Susan Demers, Elizabeth Finigan, Caryn Havens, Jonathan Klein, Peter Lalley, Michael McKee, Amanda O'Hearn, Robert Pollard, Vincent Samar, Deirdre Schlehofer, Barbara Spiecker, Matthew Starr, Anne Steider, Erika Sutter, Heidi Thompson, Adam Weis, Thomas A Pearson

NTID Subcontract Research Team: James DeCaro, Peter Lalley, Vincent Samar

Deaf Health Community Committee: Julia Aggas, Jessica Cuculick, Patrick Graybill, Angela Hauser, Ken Kelbaugh, Chris Kelley, Cindy Mann, Howard Mann, Michael McKee, Tiffany Panko, John Reid, Arlene Sankey, Audrey Schell, Anne Steider, Patrick Sullivan, Tracey Washington

ASL Translation Working Group: Robyn Dean, Susan Demers, Elizabeth Finigan, Patrick Graybill, Raylene Harris Paludnevicene, Betsy McDonald, Robert Pollard

Sign English Translation Working Group: Karen Finch, Aaron Kelstone, Vincent Samar, Kathryn Schmitz, Patrick Sullivan

Filming Team: Craig Bellaire, Ritchie Bryant, Lisa DeWindt, Patrick Graybill, Donna Gustina, Mary Beth Mothersell, Elouise Oyzon, George Postlethwait, Vincent Samar

Interface Development Team: Mike Delany, Elouise Oyzon, Vincent Samar, Heidi Thompson, ITX Corp

We also thank Joe Duckett, Steve Fasone, Tom Fogg, Brianne Testa-Wojteczko, Finger Lakes Health Systems Agency, Rochester Recreation Club of the Deaf, Rochester School for the Deaf, many interpreters, a very supportive community, and the research participants.

This work was supported by Cooperative Agreement Number U48 DP000031 from the Centers for Disease Control and Prevention (CDC). Steven Barnett is supported by grant K08 HS15700 from the Agency for Healthcare Research and Quality (AHRQ). The contents of this article are solely the responsibility of the authors and do not necessarily represent the official views of the CDC or AHRQ.



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New Developments in C-Print

by Michael Stinson, Lisa Elliot, and Pamela Francis

Students who are deaf or hard of hearing (deaf/hh) and who attend regular education (inclusion) classes along with hearing peers depend on support services to have access to classroom presentations and discussions. Often a sign language interpreter provides this support. Students who are deaf/hh also depend on support to retain the material after class in order to complete homework and other assignments. Notes taken by a peer or a professional notetaker have often provided this support (Hastings et al., 1997). A service that is increasingly being used for some students who are deaf/hh is classroom captioning or real-time speech-to-text service (Stinson et al., 1999). With classroom captioning, a service provider, who is often in the classroom, produces text as it is being spoken by a teacher or classmate and displays it on a laptop computer so that students can read what is happening in class. For the past 19 years, a group of researchers and developers at the National Technical Institute for the Deaf (NTID), a college of the Rochester Institute of Technology (RIT), has been developing and refining a speech-to-text support system called “C-Print” (the “C” is for “see” and the system’s “C”omputer-based operation). New C-Print initiatives are being supported by grants from the U.S. Department of Education, the National Science Foundation, and the NEC Foundation of America (see C-Print research at www.ntid.rit.edu/research).

The more recent C-Print research and development initiatives are motivated by three factors. First, the results of C-Print research and development projects indicate that C-Print is an effective service in providing access and supporting student learning (Stinson, Elliot, Kelly, & Liu, in press; Elliot, Foster, & Stinson, 2002). Second, use of C-Print in secondary and postsecondary programs in the U.S. is widespread. Third, the C-Print research and development team is aware that current technology and implementation

needs to be improved. Accordingly, the team has developed one new version of C-Print that works with a tablet PC and another version in which the provider is in a remote location, rather than in the classroom with students.

C-Print with Tablet PC Technology

Use of tablet PCs may significantly improve the ability to provide curricular information for deaf/hh students, particularly when a class includes both spoken and graphical information such as in mathematics and science classes. In working with tablet PCs, the research and development team is developing new options which better capture the information students need in order to learn. A tablet PC is a type of laptop computer that has an LCD screen on which the user can write using a special-purpose pen (stylus). The handwriting is digitized and can be converted to standard text through handwriting recognition, or it can remain as handwritten text. Tablet PCs also usually have a keyboard and/or a mouse for input (Wikipedia, 2008).

The team has developed two options for using C-Print with a tablet PC: a notetaking option and a speech-to-text plus graphics option. With the notetaking option, students view notes in real-time on a tablet as they are being recorded by a notetaker, whose tablet communicates wirelessly with the students’ tablets. Because the notetaker is in class, students do not have to wait until the end of class to view the notes. During or after class meetings students may add their own notes to the text. The notetaking option was developed for students who rely primarily on an interpreter or teacher to access classroom information. The handwritten notes the students view during class provide supporting information but are not the main source of communication access. These notes provide additional context that students can use to fill in information they missed while watching the interpreter or the teacher. Also, students know during class what information the notetaker is recording and can add any information the notetaker missed themselves.

The team has developed two options for using C-Print with a tablet PC: a notetaking option and a speech-to-text plus graphics option.

The team is also creating a system that can be effectively used in outdoor settings... with flexible screen display on either handheld devices or full-sized computer screens.



Pam Francis is the C-Print Pro Marketing Coordinator.

With the second option, in which tablet technology is used with speech-to-text support, a service provider uses a tablet PC to provide graphical information side-by-side with the text on the student's computer display. Students can mark the text of the real-time display produced by the provider or add their own written notes. With this option, the provider listens to the teacher or students and produces a text display of the message on the student's tablet. This newly developed technology allows the provider to produce graphics when the teacher draws a figure or writes a formula. In science and math classes, traditional typing-only C-Print is only marginally effective. If students must write down graphical information, their attention is diverted from the teacher or the text display and they may miss critical information. The new technology, which integrates graphical and textual information into the notes that students receive, may facilitate a considerable increase in comprehension of instructional materials.

Remote C-Print

A second new technology that the C-Print team is developing is a remote speech-to-text system that allows individuals who are deaf/hh to view real-time speech-to-text services in remote or nontraditional educational settings. With remote C-Print, a teacher speaks into a Bluetooth cell phone. A service provider in a remote location listens to the teacher's message via a cell phone and headset. Using the C-Print software, the provider produces and sends the text via the Internet to a designated server, and the text is then processed into a form for student viewing on a handheld device such as a smart phone or personal digital assistant (PDA).

In remote situations students are often at a disadvantage when, for example, an interpreter is at risk due to the terrain or weather conditions. Current speech-to-text technology used in the classroom cannot support information transfer to remote settings such as science field trips. Therefore, the remote C-Print initiative is seeking to provide alternative speech-to-text support for

remote and mobile learning experiences. Although some current remote speech-to-text systems can work successfully, they are hampered by the technical complexity of a multi-step setup process, restricted access to the Internet, and a text display that is only suitable for a full-sized computer screen. Development of remote C-Print is creating a system that can be effectively used in outdoor settings as well as in indoor settings (classes and meetings), with flexible screen display on either handheld devices or full-sized computer screens.

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Figure 2.
The National Center for Deaf Health Research developed the first linguistically accessible and culturally appropriate computer-based health survey with the Deaf Community.

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