Journal of the American Deafness and Rehabilitation Association
Year 2007, Volume 40, Number 2 Complete

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JADARA

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THE MENTAL HEALTH NEEDS AND PERSPECTIVES OF CULTURALLY DEAF OLDER ADULTS LIVING IN TWO COUNTIES IN FLORIDA

David M. Feldman, Ph.D., Macon State College, and William Kearns, Ph.D., University of South Florida

Abstract

The objective of this study was to develop an understanding of the perceptions and needs of Deaf older adults related to mental health services in their communities. There has been little research on this population and few studies have been published that explore mental health and the Deaf older adult population. A survey of two associations for the Deaf in Florida sampled attitudes of participants who were 55 years old or above and considered themselves to be “culturally Deaf.” Questions were developed to better understand the perspectives of Deaf older adults related to current availability of services, desire for services, and how services should be organized. The data suggested that culturally Deaf older adults were aware of available services and desired more services. Deaf older adults stated specific services they believed they needed, such as dementia resources and mental health services. Deaf older adults indicated a clear preference for services to be specific to their needs and separate from hearing older adults which has implications related to the development of programs and services for this population.

As the aging population in the United States increases so too will the Deaf older adult population. One of the very few population statistics related to older deaf adults was published by the Gallaudet Research Institute (GRI) in 1994, and suggested that the deaf and hard of hearing elderly population at that time totaled more than 11 million and made up about 29.1% of the population of all elderly people in the United States (Holt & Hotto, 1994). Another earlier statistic projected the number of deaf and hard of hearing elderly people by 2015 to be 12.3 million (Brown, Hotchkiss, Allen, Schien, & Adams, 1989). More current demographic information has not been collected or made available. Regardless, the number of elderly deaf and hard of hearing individuals continues to rise with the advent of the baby boomer generation.

The terms deaf, hard of hearing, and culturally Deaf cover several different groups and include not only those who were born deaf but also those who became deaf as a child, adult, or older adult. This topic has been explored in previous literature (Feldman, 2004; Paul and Jackson, 1993; Reagan, 1990) and the interest in this study is those Deaf older adults that are, and consider themselves to be, culturally Deaf (as indicated by the
capitalization of the letter “D”\), and use American Sign Language (ASL) as their primary means of communication.

The purpose of the current study was to survey Deaf older adults to 1) obtain a better understanding of perspectives on, and awareness of, currently available mental health services, 2) identify opinions related to desired mental health services, and 3) identify preference as to preferred delivery of future mental health services.

Although there is a fair amount of research on mental health and Deafness (Glickman, 2003; Paul and Jackson, 1993), there appears to be a significant gap when it comes to studies involving Deaf older adults. While it is clear that the Deaf older adult is a significant and growing part of the Deaf community, little is known about how they perceive mental health services or if they have any specific desires for services. Currently no federally funded, standardized, or formalized national program is providing services to or examining the culturally Deaf older adult population (Feldman, 2005). Although a variety of organizations do provide some kinds of informal services, these organizations are often branches of Deaf social clubs or various service agencies designed to support either general adult Deaf or deaf and hard of hearing populations. The majority of them are not specifically focused on Deaf older adults (Lane, Hoffmeister, & Bahan, 1996). Pullen and Kyle (1997) express concern at the lack of available and appropriate services for Deaf older adults and suggest that the Deaf community, by default, is often the main provider of services. However, they also point out that, as one becomes older and less mobile, participation in community events may become more difficult.

Sela (1986) surveyed senior centers and service providers to determine whether deaf and hard of hearing elderly people were being served and, if so, to what extent. The results of this dated study reveal that only 9% of the providers had services specifically designed for deaf and hard of hearing elderly people. The Gallaudet Research Institute predicted in a 1989 national demographic study on deafness that the demand for services by deaf and hard of hearing elderly people will continue to grow, exceeding both the current demand for services and current availability (Brown et al, 1989; Hotchkiss, 1989).

Clearly, a gap exists in the literature related to this topic, and more study is needed to achieve a complete and up to date understanding of the
issues involved with the current state of mental health services to Deaf older adults. The purpose of this study was to examine the reports of a large group of Deaf older adults with respect to their perceptions and needs related to mental health services. It is hypothesized that Deaf older adults will report a general lack of both awareness of, and availability for, mental health and age related services. It is also hypothesized that Deaf older adults will have specific preferences and desires as to the priorities for services and preferences regarding presentation of services.

**Methods**

The survey was designed for use with a Deaf older adult population and questions were created with the intent of examining mental health issues related to this specific population. Survey items were selected based on the research question and developed to measure the perceptions of Deaf older adults related to currently available and needed services.

Surveys (Table 1) were completed by two groups of Deaf older adults attending meetings of two associations for the Deaf in Broward County and Palm Beach County, Florida. All individuals who participated in the study were over 55 years old and used American Sign Language as their primary means of communication. A total of 77 surveys were completed at the two sites.

Each survey contained 18 questions. Four questions solicited demographic information (gender, age, county of residence, and type of residence). Two of the questions referred to existing mental health services for Deaf older adults and three questions asked about preferences for future mental health services for Deaf older adults. The remaining 9 questions asked the respondent to select specific services they would be interested in receiving.

Survey questions were selected in the absence of any directly applicable surveys in the related literature that would be appropriate for both an elderly and culturally Deaf (i.e. English second language) population. Thus, this study should be considered exploratory rather than confirmatory. Specific questions were selected based on services typically offered to older adults, language and cultural concerns, and awareness of available services.
The demographic questions (age, gender, residence, and county) were scored by matching the participant's selection to a corresponding numerical code depending on the number of available choices. Gender and Country of Residence each allowed for two choices. Age was broken down into 7 age groups with 5-year intervals, and Type of Residence was broken down into 4 choices. The means of these categories were compared and are discussed in the results section.

Questions related to the awareness of mental health services were scored either yes, no, or not sure/don't know response. Yes responses were coded as a 1, no was coded as a 0. These were analyzed and are discussed in the results section. The three questions that asked about specific services for the Deaf had only a choice of yes or no. Yes was scored as a 1 and no was scored as a 0.

The list of specific services participants would like to see provided consisted of 9 health related services from which participants were asked to select. Participants could select as many services from the list as they wished. The various services on the list were then coded numerically from 1-9. Selections were analyzed through factor analysis and the services with the most remarkable scores are discussed below.

Results

Demographic Analysis

Participants were predominantly female (63.6%); the ages of the participants ranged from 55 to 89, with the highest response rate (26.0%) belonging to those in the 71-75 age range. 55.8% of the participants were from Palm Beach County with the remainder residing in Broward County. Most of the participants lived in their own home or apartment (80.5%), with some living in the home or apartment of family members (18.2%). Only one lived in a nursing/assisted living facility (with only hearing residents).

Survey questions related to the needs and perceptions of this group revealed that while only 42.9% indicated that they were aware of overall available services for senior citizens in their respective counties, only 13% responded that they felt mental health services provided for Deaf senior citizens were adequate. 94.8% responded that they would be interested in
more mental health services for Deaf senior citizens; and 77.9% responded that they would prefer to have services offered separately (for Deaf senior citizens only). Additionally, 58% of the participants responded that they would not know where to go if they needed mental health services.

In order to determine which specific services for Deaf senior citizens the participants would prefer to be provided, participants were asked to select services they would want from a provided list. The most frequently selected service was dementia resources (68.8%), with mental health counseling selected by 61.0% of the participants. Social activities (55.8%) and general health information (53.2%) also scored high as a perceived needed services by Deaf older adults.

Scaling

Two distinct features emerged from the factor analysis principal components analysis (Table 2). Factor 1 taps the participants interest in General Health and Service needs for Deaf older adults. From the participants’ perspective, this is a list of what services perceived to be most valuable. Factor 2 contains items more specifically associated with mental health services and how these services might be made most appropriate with Deaf older adults. Survey results indicated that in addition to a high need for the provision mental health services, there was a strong preference that these services should be provided to Deaf older adults without the participation or involvement of hearing older adults. The rotated factor structure (varimax rotation) is presented in Table 3.

Discussion

The findings of this study illustrate the difficulties involved in obtaining services for Deaf older adults. In general, Deaf older adults do not know where to go to get mental health services, want specific services, and feel that if these services are provided they would participate if they were tailored to fit their specific needs.

These results support the hypothesis that Deaf older adults would report a general lack of awareness and availability of mental health and age related services, and that Deaf older adults had specific preferences for both general services and mental health services (which appeared to be related to obtaining information about such services). There was a preference for services to be provided separately from hearing older adults and specifically tailored to Deaf older adults, which would include presentation in ASL.
Even if similar aging and mental health related services exist for hearing older adults, there is a clear lack of awareness of those services among the Deaf older adults. The majority of participants were unaware of what services were available for Deaf senior citizens and more than half responded that they would not know where to go if they needed mental health services. A lack of inclusion in the initial planning and development of services for Deaf seniors by service providers, lack of media advertisements with closed captioning, lack of provision of interpreter services at planning meetings and senior events, and a general lack of awareness by the hearing planning committees related to the needs, or even existence of Deaf older adults contribute to this problem. Conversely, the Deaf older adult who typically does not seek out mental health services is unlikely to make their presence known and inquire about available or wanted services. These concepts are not particularly new and coincide with other data collected and published on Deaf adults (Feldman, 2005; Glickman, 2003; Lane, et al, 1996).

These results show a clear desire for additional mental health services. The majority of participants responded that they believed that mental health services were inadequate in their respective communities, and almost all responded that they would be interested in more mental health services. It is also noteworthy that most of the participants responded that they would prefer those services to be separate from services for hearing seniors. This is understandable considering the importance of language and culture when providing services to the Deaf, and the desire for direct communication with service providers.

As to the specific services that the participants would like to see established, the one most selected was “Dementia Resources.” The Deaf older adult may be aware of “dementia” as a broad term, but may lack a full appreciation of the concept due to language barriers. The Deaf older adult may see the term “Alzheimer’s disease” several times a day in the media or in magazines, but not fully be able to comprehend the accompanying article or story. Additionally, very few mental health or medical providers know ASL or have even a basic understanding of Deaf culture, making the direct communication of dementia information from professional to Deaf client less likely.

Another highly selected service was “Mental Health Counseling,” which is not surprising. Current information (Ables, N., Cooley, S.,
Deitch, I., Harper, M., Hinrichsen, G., Lopez, M., Molinari, V., 1998) on geriatric populations has yielded data that suggests older adults in general experience a significant proportion of mental health issues (e.g. dementia, anxiety, and depression) in addition to more serious problems (e.g. suicidal ideation, delirium). The Deaf older adult is not immune to such mental health problems and, while no hard data exists, it is likely that they experience these same mental health issues on a scale parallel to their hearing counterparts. However, as with younger Deaf adults, the exact etiology and symptomology might appear different. It is important to remember that the participants in this study were not asked about seeking these services only for themselves, but also in consideration for an elderly spouse, or other elderly family as well.

Over half the participants selected “General Health Information”. It is likely that the rationale for this selection is similar to the rationale of “Dementia Resources” and “Mental Health Counseling.” There clearly exists a lack of available and understandable general health information, and too few service providers are accessible to Deaf older adults.

“Social Activities” was also a category selected by more than half of the participants which may reflect a lack of activity within the Deaf older adult community. It may be the result of a primary dependence on the Deaf community, or Deaf older adult community, for social activities and entertainment. The studied sample of Deaf older adults is probably more used to Deaf social recreational events, which revolved around their “Deaf clubs.” It is possible, that with the decline of Deaf Clubs, both in membership and financial support, an important social resource has been lost, or reduced. Deaf clubs may be considered by many in this age group to be a crucial part of their social activity( Lane, et al, 1996). The high rate of the selection of “Social Activities” may also be an awareness on the part of Deaf older adults to the connection between social interaction and positive mental health.

Limitations of This Study

When interpreting the present study’s results, consideration should be given to its limitations. This study was limited to only those Deaf older adults in two counties of Florida. However based on other data (Feldman, 2005) the gap in services for the Deaf older adult exists throughout the rest
of this state and the U.S. in general. Only those physically able to attend a meeting of one of the two associations for the Deaf participated in this study. Those Deaf older adult who were unable to attend such meetings, due to illness or other issues, may have responded differently than this group.

Conclusion

While much more research is needed to investigate the needs of the Deaf older adult, this study provides a starting point to better understand some of their needs. The data presented here suggest that some significant problems exist in the delivery of mental health services to the Deaf older adult. Deaf older adults were generally unaware of what services were available and where they would go if they needed mental health services. They clearly indicated a preference for delivery of services that would be separate from hearing older adults and what specific services they feel they need.

As the numbers of elderly people in America increases, the Deaf older adult should not be forgotten. For members of this group to benefit from age related services, attention must be placed on their specific language and cultural needs. It is also important to consider how we communicate information about available services to this group. To develop appropriate services for the Deaf there must be an inclusion of Deaf older adults, Deaf community leaders, and Deaf advocacy groups in the planning and implementation. Advertisements for services must be directed towards Deaf older adults and include closed captioning, videophone or text telephone numbers, and be posted in Deaf community or association publications and meeting places. Service providers that can sign and are familiar with Deaf culture must be provided to make sure that the Deaf audience can clearly understand the information being presented. Services that are not developed with the above criteria in mind are likely to be unknown or ignored by Deaf older adults, or worse - disappointing and meaningless for those who might participate.
References


Table I
Survey Items

1. Do you feel that you are aware of the mental health services for senior citizens that are available in your county?
   a. Yes
   b. No
   c. Not sure

2. Do you feel that the mental health services provided for Deaf senior citizens are adequate in your county?
   a. Yes
   b. No
   c. Don’t Know

3. Would you be interested in more mental health services for Deaf senior citizens in your county?
   a. Yes
   b. No

4. What specific services for Deaf senior citizens would you like to see provided in your county?
   (Circle all that apply)
   a. Mental health (i.e. depression) counseling
   b. Alcohol dependence treatment
   c. Substance abuse (drugs) treatment
   d. Gambling addiction treatment
   e. Dementia (i.e. Alzheimer’s Disease) resources
   f. Social activities
   g. Legal assistance
   h. General health information
   i. Financial Assistance

5. Would you prefer these services to be
   a. Separate (for Deaf senior citizens only)
   b. Inclusive (both Deaf and hearing senior citizens)

6. If you needed mental health services, would you know where to go
   a. Yes
   b. No
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<td>2 = With family</td>
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<td>3 = Nursing/ALF w/ hearing and Deaf</td>
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### Table 2
Principal Components Matrix

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<td>3 = Nursing/ALF w/ hearing and Deaf</td>
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Abstract

This paper describes the methodological process involved in the transliteration, from English into American Sign Language, of the 12-item Short Form Health Survey, and gives an example of how these future physicians can work with members of the Deaf community to improve the community’s overall health and well being. The paper will also provide clear evidence of the need for strong support for research, as well as the need for widespread collaboration and participation on the part of the Deaf community.

Introduction

Working together, the Deaf Community Services of San Diego, Inc. and the Community Outreach Program of the Rebecca and John Moores UCSD Cancer Center (UCSD) concluded that there was a need to create health professionals who were more sensitive to the linguistic, cultural, communication, and learning style preferences of the Deaf community. In 2003, the National Cancer Institute funded a partnership to develop and evaluate an American Sign Language, Deaf Culture, and Cancer Control Training Program for Medical Students. Through the partnership with Deaf Community Services of San Diego, Inc; Gallaudet University; the University of California San Diego’s School of Medicine; and the Moores
UCSD Cancer Center, the training program is preparing a cadre of future physicians to meet the health care needs of the Deaf community. The Deaf community helps train the medical students by participating in the training program and in the student-led research activities and health seminars which help the students gain cultural and linguistic competency.

By the end of the two-year program, each of the medical students, who are also known as “ASL Fellows,” will have: 1) a basic proficiency in ASL (American Sign Language); 2) respect for the Deaf community’s cultural beliefs, values, and traditions, 3) competency in using communication and learning styles preferred by the Deaf community; 4) expertise making presentations to Deaf audiences; 5) a strong understanding of the use of interpreters in the clinical setting; 6) proficiency in cancer control; and 6) knowledge and experience in a variety of research methods needed to enhance the Deaf community’s well being. These physicians will serve as clinical leaders and role models in advancing and championing the health care needs of the Deaf community through research and raising other physicians’ awareness of the needs of the Deaf community. The students will also lead an undergraduate Pre-Health (careers) Club that encourages pre-health students to learn ASL and encourages students taking ASL to consider health and welfare careers that would better serve the Deaf community.

Creating New Knowledge for the Deaf Community

All medical students at UCSD’s School of Medicine must complete an Independent Study Project (ISP) as part of their graduation requirements. The students participating in this ASL Fellows Training Program are encouraged to select an ISP related to advancing the health and well being of the Deaf community.

Several medical students became interested in testing the validity of commonly used standardized instruments so they could be used with confidence when administered to members of the Deaf community. Such instruments are used in medical and mental health settings to evaluate patients’ well being or changes that occur as the result of an intervention (Ware, Kosinski, Turner-Bowker, & Gandek, 2002). Before a standardized instrument can be used with confidence it must first be administered to a sample of members from the community with which it will be used to
determine if the questions are valid when used in that community and what range of scores would be considered within the range of normal when the instrument is used in that community. (Apolone, & Mosconi, 1998; Geisinger, 1994; Guyatt, 1993). Very little attention has been devoted to assessing whether the available standardized instruments are valid for use with the Deaf community. (Brauer, Braden, Pollard, & Hardy-Braz, 1998). Given the Deaf community’s unique culture and language, it is essential that psychometric instruments be validated with this community before being used as a means of assessing health and well being with its members.

Methodology

Participating medical students identified the Short Form Health Survey (SF-12) as an instrument that is commonly used in health care and research settings and, therefore, would be appropriate to transliterate, validate, and norm for use with the Deaf community. The SF-12 is a 12-item instrument that was derived from the 36-item Health Survey (SF-36) (Ware, Kosinski, Turner-Bowker, & Gandek, 2002). It produces an accurate assessment of the test taker’s physical functioning and mental health.

The original, standardized instrument was written in English and uses some words, phrases, and idioms that might not be easily understood by Deaf individuals whose primary language is ASL and whose English literacy may be low. For example, the American English expression of “feeling blue” may not have the same meaning for deaf Americans whose primary language is ASL as it does for English-speaking, hearing Americans. A transliteration from English to ASL, rather than a direct translation, might be needed to make such a colloquial expression achieve the same conceptual intent for the Deaf community.

There are well-established steps to translating and validating psychometric instruments for use with additional communities (Guyatt, 1993). The first step in the validation process is to have a bilingual focus group of at least 5 members of the target community who are fluent in both languages, translate the instrument from English into the subjects’ primary language – ASL in this case, for the Deaf community. For the “forward translation,” the English language version of the SF-12 was distributed to the focus group members prior to convening the focus group, to allow time to reflect on the statements and develop preliminary translations. All
members of the focus group then gathered and systemically reviewed the group members' translations for each of the items. They decided what they believed was the best ASL translation for each item. They then captured the signed translation on videotape and reviewed the signing to assure it was clear, as well as consistent with their preferred translation.

The second step is to recruit a second focus group of at least five different members of the Deaf community, who are equally fluent in both languages to back translate the ASL version of the SF-12 into English. For this back translation, the participants were given no prior knowledge of the original English language version of the instrument. The group members watched the video presentation of each item from the SF-12 as it was signed in ASL and then independently wrote the English translation on paper. After each item had been viewed and individually translated, the group members collectively discussed their English translations. Where there were discrepancies between the English translations from ASL and the original English item, they were asked to discuss possible translations of the item until they reached consensus on an ASL translation that would best represent the original English version.

Both the forward and back translation focus groups also had the option of adding new items to make the instrument more linguistically accurate or culturally appropriate to the Deaf community. The back translation focus group had the final say on which translations and new items would be included in the final videotaped version of the SF-12-ASL that would be used to test the validity of the ASL version of the SF-12 with members of the Deaf community.

Before members of the Deaf community engage in these focus groups, they are formally consented just as they would be before participating in any research process. For the consenting process, potential participants are given an in depth explanation of the research project and what they will be asked to do if they become part of the research project, as well as their rights as a participant in a research project, including the opportunity to withdraw from the project at any time. Only after they are fully informed and have consented to participate in the project, do they participate in the focus groups. Since the entire process of translating the SF-12 into ASL was videotaped to allow the research team to review the process should questions arise at a later time, the focus group participants were also asked to sign a photo
release form, both for the process itself and to consent that their videotape could be used for program promotion and educational purposes.

Description of the Focus Group Sample

Two separate focus groups were used in the transliteration and validation of the SF-12; five in the forward translation and five in the backward translation. Five were pre-lingually deaf adults and five were certified ASL interpreters. All ten participants were native ASL signers and fluent in English. The educational background of the Deaf focus group members was relatively high: all five had at least some college education and three had graduate degrees. All of the interpreters had college degrees, and three had graduate degrees in communication or ASL-related fields. Diverse participants included seven women and three men. The average age of the focus group members was 37 with a range between 27 and 40 and a standard deviation of 4.7.

Results

The format of the SF-12 presented problems since there were several items where a single statement was followed by two or three response opportunities. While it is simple for the English reader to refer back to the original item on the instrument, this presents problems for the signed version of the items. The groups’ solution for the signed version was to repeat the introductory statement for the items. The focus group members also observed that a respondent will often read a survey item more than once to assure that they have a clear understanding. To assure a comparable opportunity for the SF-12-ASL, the focus group members recommended that each question be shown twice with a short break between each signing and that they be given the option of seeing the signed item again if needed.

The focus groups’ forward and back translated nine of the original 12 English items into conceptually accurate ASL without complications. To the degree possible, simple, universal signs were selected for these items so that they would be easily understood by all members of the Deaf community. (See Table 1 for the original items and the ASL Gloss translation – the closest English version of the ASL signed version).
For three of the items there was no direct translation between English and ASL, making a transliteration necessary. (See Table 2) The back translation focus group could not generate anything from the ASL versions that closely approximated the original English versions of those items. The discussion involved in the translation of these three items provided stark insights into the challenges faced when translating relatively simple English phrases into ASL. For example, in item #3 with its two sub-items, ASL translations were provided for the entire question (i.e., “During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your physical health?”). Then, for the sub-questions the phrase, “during the past 4 weeks” was added to the statements: a) “accomplished less than you would like” and b) “were limited in the kind of work or other activities.”

For item #3, the phrases “accomplished less than” and “less carefully than usual” did not have direct ASL translations. Therefore, the group decided to use the sign “100% you not achieve” to convey the underlying meaning of the statement.

For the remaining three items, the SF-12 uses the past tense, passive statements which are not easily translated into ASL. For example, this passage is difficult to translate into ASL: “have you had any of the following problems.... as a result of any emotional problems”? The members of the back translation group concluded that the meanings of the original statements were not evident in the ASL translations, thus they offered new ASL translations using a more active voice.

Finally, the forward focus group noted that most Deaf individuals work and interact with people who hear. The focus group members worried that deaf people might answer the survey quite differently depending on whether they were relating to a context in which everyone was Deaf verses a situation in which nearly everyone was hearing. Therefore, they recommended adding three questions to the end of the survey to address this concern (See Table 3). The back-translation group reviewed the three additional items suggested by the forward translation group and decided to accept only one of them: “Would your answers to the previous questions be different if applied to a Deaf community?” The members of the group were concerned that the other two questions were too wordy and specific in nature.
Discussion

Of the original 12 items on the SF-12, only nine were easily translated by the focus group participants, and even those required some minor discussion of the specific signs and order of signs to be used in order to arrive at the closest possible translation into ASL. The remaining three items required extended discussion to arrive at the closest approximation for the forward translations and those translations were rejected by the back-translation focus group and new ASL translations were developed for the final SF-12 instrument. These focus groups’ experiences translating the SF-12 into ASL underscore the problems that arise when “on-the-fly” (with little opportunity for forethought and contemplation of how best to express a concept for the Deaf individual) ASL interpretation is used to translate a standardized instrument for a person with limited or no grasp of English. Without a standardized ASL translation on video, there can be no assurance that the same instrument is being administered to deaf persons as it is to hearing people, or even that all deaf persons are receiving the same instrument.

An additional question arose for the focus groups as they worked on the forward and backward translations of the items: “What would be the social context in which the deaf person would be responding to the instrument?” Members of the focus group felt Deaf employees, for example, may experience communication barriers in numerous ways that could influence their response to a standardized instrument: 1) on-the-job training; 2) socializing with co-workers; 3) department/staff meetings; 4) work related social functions; and 5) receiving instructions and supervision. It has been noted that some deaf individuals attempt to avoid the difficulties such barriers create in the workplace by avoiding social interactions or pretending to understand communication from hearing people. Unfortunately, such attempts to disguise their deafness typically result in feelings of frustration, embarrassment, isolation and stress (Gunnel, Wennberg, & Kinteberg, 1998; Steinberg, 1999). More importantly, lack of communication and social support increases stress, which negatively impacts one’s emotional and physical health. Thus the focus group participants felt strongly that the Deaf persons responding to the items on the SF-12 might give different answers if they were told to envision themselves living and working in a Deaf environment versus a predominately hearing environment. Being unable to resolve how this might affect the participants’ responses, both focus groups
opted to add a question that specifically addressed that concern. So as not to alter the order of the original items, that one new question was added as the last item in the survey and asked as a global question for all items.

The ASL translation of the SF-12 has been captured on video according to ASL protocol. ASL protocol requires that the signer uses linguistically appropriate facial expressions to convey the message, uses signs that are free of colloquialism, wears clothing that contrasts with skin color but is not distracting to the viewer, does not wear distracting jewelry and stands in front of a solid background. After the signed translations were captured on video, the video editor employed culturally sensitive editing techniques. Before each item was signed, a black screen appeared with the number of the item that was about to be signed. This allows the viewer time to locate the number of the question about to be signed with the number of the English statement of the SF-12 instrument. The same number is then repeated a second time and then the same item is signed a second time. Then, the signer appeared on the screen and signed the ASL translation. A blank screen then appeared for 10 seconds between items to give respondents time to record their answer on the survey. By having this designated time interval between items, the video does not need to be stopped and restarted for each item. Thus, the full ten-minute SF-12-ASL video was played from start to finish without interruption unless a Deaf participant requested to view an item again. Participants were told they can see each item as many times as needed to understand the signed statement and respond to it. The final edited video represents the best approximation of the SF-12 in ASL and is ready for large scale administration to determine the instrument’s reliability and validity within the Deaf community.

Future Plans

The next step in the process of testing the usefulness of the SF-12 for the Deaf community, which is already underway, is to recruit members of the Deaf community to complete the ASL-translated version of the SF-12, now called the SF-12-ASL. When validating an instrument, the recommended sample size is at least 300 subjects or 10 times the number of items if the instrument contains more than 30 items (Tabachnik & Fidell, 2001). Thus for validating and norming the 13-item SF-12, the ideal sample size will be a minimum of 300 participants.
In the validation process, the research participants should ideally be recruited through a variety of strategies to assure the greatest possible diversity among the participants. The ideal sample will be diverse in terms of age, gender, religion, ethnicity, geography, socioeconomic status, sexual orientation, and so forth. The more diverse the characteristics of the participants from the Deaf community, the greater will be the confidence in the instrument when used with community members at large. It is important for the members of the Deaf community to be aware of the importance of their personal participation to the overall value of a standardized instrument. With this in mind, future plans include the continued dissemination of education to the Deaf community about what is involved in research studies and why everyone should explore research participation opportunities with an open mind when they are invited to consider joining a study.

For the validation study of the SF-12-ASL, the medical students will be assisted by undergraduate students from the UCSD Pre-Health Deaf Club whose ASL is at an advanced level, as well as by other members of the education research team. Recruitment is done through Deaf community service organizations, Deaf schools, universities with large Deaf student populations, the health seminars offered throughout California, and at social events. Between their first and second years, the medical students attend a four-week language immersion program at Gallaudet University in Washington D.C. where students can also recruit students, faculty, and staff participants whose primary language is ASL. Faculty at Gallaudet will also help to connect the students with members of the region’s Deaf community.

As a bona fide research undertaking, the study validation of the SF-12-ASL must first be reviewed and approved by a federally regulated Institutional Review Board of the research team’s institution. Just as with the focus group participants, the individuals who agree to test the SF-12-ASL will receive a thorough explanation of the research project and be given the opportunity to participate. For this particular study, before participating in the data collection, all participants will be asked to sign an “informed consent” document. Members of the Deaf community who are invited to join the study will be reminded that participation in all research data collection is voluntary and that subjects may stop participating at any time. Those who complete the study will have enjoyed the refreshments offered during the process and receive a small gift as a “thank you” for participating.
This project demonstrates the dynamic work that can be accomplished on behalf of the Deaf community when its leadership seeks and finds academic collaborators within an empathic university. While the Deaf community is reported to be insular and distrusting of the medical and research community, the experiences with this project demonstrate that this barrier can be successfully overcome by using culturally competent, linguistically proficient, and trusted members of the community to work as the interface between the organization and the community. With that approach, the community members gain knowledge and skills that can be used to further enhance the community’s well being.

Finding the right incentives is also important in attracting members of the community to research studies. With the help of insights gained from focus groups with grassroots members of the Deaf community, the research team correctly identified the community’s pleasure in gathering together socially. By implementing this research project around a meal and a social gathering, and by conducting the program entirely in American Sign Language, the research team made the research experience more positive and enjoyable for the participants. By taking the study into familiar community settings, this increased the Deaf community’s barriers in gaining access to research projects.

This community-campus partnership has been underway since 1997, working to develop and test new ways to increase the Deaf community’s access to health information and care, prepare future physicians who will be culturally competent when caring for members of the Deaf community, and developing a cadre of instruments that have been validated for use with the Deaf community. As a result, the scientific literacy of the region’s Deaf community is increasing and they are seeing the direct benefits of research participation, an outcome that has attracted additional Deaf participants and their friends to subsequent research studies.

Once 300 members of the Deaf community have completed the instrument, a confirmatory factor analysis can be run to determine if the SF-12-ASL’s is valid when used with members of the Deaf community. If responses to the 12 ASL versions of the questions cluster in a similar pattern as the English version, it will be found to be valid. Then further analysis will be done to establish what span of responses will be considered within normal limits when the instrument is used with members of the Deaf community. If the responses do not cluster as would be expected from past...
work validating the SF-12, then an exploratory analysis will be conducted with the data to see if other patterns emerge from the data that might provide beneficial insights. Given the enthusiastic support this project has received from the Deaf community, the data collection should be able to be completed relatively quickly. If the confirmatory factor analysis demonstrates that the SF-12 is valid for use with members of the Deaf community, the next step will be to alert the medical and scientific community of the validation and norming of the ASL version of the SF-12-ASL, so that it can be put into use when caring for, or conducting health research within, the Deaf community.

Conclusion

Campus-community partnerships can lead to the creation of significant improvements in the health and well being of the Deaf community. Community leaders are encouraged to reach out to their local universities to seek collaborations with interested faculty who share the common goal of improving the health and well being of the Deaf community.

Acknowledgements

This project was underwritten with grants R25 CA101317 and R25 CA65745 from the National Cancer Institute, the California Endowment the Alliance Healthcare Foundation, the San Diego Affiliate of the Susan G. Komen Breast Cancer Foundation, the UCSD Academic Senate, the National Institutes of Health, Division of National Center on Minority and Health Disparities EXPORT Grant P60 MD 00220, the NCI Minority Institution/Cancer Center Partnership Program Grants U56 CA 92079 and U56 CA 92081. The American Cancer Society generously provided educational materials for the project. The partnership acknowledges the field assistance of Patricia Branz, Shane Marsh, Adam Stone, Jill Bartok, and Kirsi Grigg. The partnership also wishes to acknowledge the supportive guidance given by Carol Padden, Ph.D., UCSD Professor of Communication; Leslie Elion, JD, community advocate; Raymond Trybus, Ph.D., and Executive Director of Deaf Community Services of San Diego, Inc.; Thomas Galey, MS, and past Executive Director of Deaf Community Services of San Diego, Inc., (1998-2003); Maria Savoia, MD, Vice Dean for Medical Education, UCSD School of Medicine; and Carol Kelly, Ph.D., and Dean of Admissions, UCSD School of Medicine. The authors also thank Edward W. Holmes, MD, Vice Chancellor for Health Sciences, Dean, UCSD School of Medicine,
the late Barbara Brauer, Ph.D., Gallaudet University, I. King Jordan, Ph.D.,
former President, Gallaudet University, and Linda Lytle, Ph.D., Professor
at Gallaudet University for their enthusiastic supportive leadership, and
Nina Treiman, counselor at California State University, Northridge, Greater
Los Angeles Agency on Deafness, Inc; for coordinating the research study
at their site.

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References


<table>
<thead>
<tr>
<th>Original Item #</th>
<th>Original English Item</th>
<th>Back Translation to English</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>In general, would you say your health is: excellent, very good, good, fair, poor?</td>
<td>Rate your health! Excellent, pretty good, good, fair, poor?</td>
</tr>
<tr>
<td>2</td>
<td>The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much? 2a. The next questions are related to your everyday activities. Does your health limit your daily activities? 2b. The next questions are related to your everyday activities. Does your health limit your daily activities?</td>
<td>2a. The next questions are related to your everyday activities. Does your health limit your daily activities? If so, how much? Can you walk up the stairs?</td>
</tr>
<tr>
<td></td>
<td>a. Moderate activities such as moving a table, pushing a vacuum cleaner, bowling, or playing golf</td>
<td></td>
</tr>
<tr>
<td></td>
<td>b. Climbing several flights of stairs</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>During the past 4 weeks, how much of the time have you had any of the following problems with your work or regular daily activities as a result of your physical health? 3a. In the past 4 weeks, has your physical well-being been at 100%? 3b. In the past four weeks, has your physical well-being been at 100%?</td>
<td>3a. In the past 4 weeks, has your physical well-being been at 100%? Did not achieve 100% 3b. In the past four weeks, has your physical well-being been at 100%? Too limited to achieve 100%</td>
</tr>
<tr>
<td></td>
<td>a. accomplished less than you would like</td>
<td></td>
</tr>
<tr>
<td></td>
<td>b. were limited in the kind of work or other activities</td>
<td></td>
</tr>
<tr>
<td>The Nine Items Directly Translated Items (Translated Without Complication)</td>
<td></td>
<td></td>
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<td>---</td>
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<td></td>
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<tr>
<td><strong>6</strong></td>
<td>How much of the time during the past 4 weeks…</td>
<td></td>
</tr>
<tr>
<td>a. Have you felt calm and peaceful?</td>
<td>6a. During the past 4 weeks, have you felt calm and peaceful?</td>
<td></td>
</tr>
<tr>
<td>b. Did you have a lot of energy?</td>
<td>6b. During the past 4 weeks, have you felt energetic?</td>
<td></td>
</tr>
<tr>
<td>c. Have you felt downhearted and depressed</td>
<td>6c. During the past 4 weeks, have you felt sad and depressed?</td>
<td></td>
</tr>
<tr>
<td><strong>7</strong></td>
<td>During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc)?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>In the past 4 weeks, how has your emotional and physical state affected your social life (i.e. visiting family and friends?)</td>
<td></td>
</tr>
<tr>
<td>Original Item #</td>
<td>Original English Item</td>
<td>These Forward Translations to ASL Rejected by Back Translation Group</td>
</tr>
<tr>
<td>----------------</td>
<td>-----------------------</td>
<td>---------------------------------------------------------------------</td>
</tr>
<tr>
<td>4</td>
<td>During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?</td>
<td>In the past 4 weeks, how does your emotional state (i.e. depression or worry) affect work and daily activities? Do you perform your work and daily activities in a cautionary mode?</td>
</tr>
<tr>
<td>5</td>
<td>During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?</td>
<td>In the past 4 weeks, has your work and daily activities been affected by your physical condition?</td>
</tr>
</tbody>
</table>
Table 3. Suggested Items for the Survey

<table>
<thead>
<tr>
<th>New Item #</th>
<th>Forward Focus Group’s Suggestions</th>
<th>Backward Focus Group’s Decision</th>
</tr>
</thead>
<tbody>
<tr>
<td>8</td>
<td>Would your answers to the previous questions be different if applied to a Deaf community?</td>
<td>Accepted</td>
</tr>
<tr>
<td>9</td>
<td>a. In the last 4 weeks, how often did your emotions interfere with work and everyday activities in a hearing environment?</td>
<td>Rejected</td>
</tr>
<tr>
<td></td>
<td>b. In the last 4 weeks, how often did your emotions affect your work and everyday activities in a Deaf environment?</td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>a. In the last 4 weeks, how often did your health interfere with work and everyday activities in a hearing environment?</td>
<td>Rejected</td>
</tr>
<tr>
<td></td>
<td>b. In the last 4 weeks, how often did your health affect your work and everyday activities in a Deaf environment?</td>
<td></td>
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AN ATTEMPT OF SCHOOL COUNSELING PRACTICE AT AN ORAL SCHOOL FOR THE DEAF IN JAPAN: FROM A SOCIO-CULTURAL POINT OF VIEW

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Abstract

In Japan, the aural-oral approach has long been the dominant educational method in the schools for the deaf. The author worked in an aural-oral school for the deaf for 5 years. This paper examines the psychological problems experienced by deaf children in that oral situation and the role of the counselor from a socio-cultural point of view. Two cases, in which both clients were high school level students who were integrated into the local primary and middle schools and then returned to the school for the deaf at the high school level will be discussed. During their integrated periods both clients seemed to have little experience of deep communication with ‘language’ which would help them develop social skills and to be self-reflective. The failure in developing this ‘language’ seemed to have resulted in producing some psychological problems. Through examining the counseling processes, this paper discusses the roles of counselors in such an oral situation for deaf clients.

In Japan, most of the schools for the deaf have been using the aural-oral method, and have had a negative attitude toward the use of the signed language in the classroom, though recently some deaf schools began to implement some sort of signing from the preschool level. The typical situation in those aural-oral schools is as follows. The deaf children are trained orally at the preschool level, and then, many of them are integrated or mainstreamed into the local primary schools, or into the hard-of-hearing classes attached to those schools. The rest of the deaf children enter the primary programs of the schools for the deaf. Generally speaking, at younger ages the aural-oral method tends to be applied more strictly, so the teachers of preschool and primary school levels are reluctant to use signing for communication and instruction. At the middle and high school levels some teachers are using some sort of signing (Torigoe, 2004).

Sign language survived a period of oppression in the schools for the deaf. Deaf children learned sign language from other older children or the children from deaf families, and continued to use it in their everyday’s lives; for example, in the dormitories, at the playground, and in the classroom when their teachers were absent. After their graduation, they kept contact with each other, and subsequently established and maintained the deaf
community (Lane, 1984, Van Cleve & Crouch, 1989). The deaf community is not just a group of disabled people, but rather a linguistic minority society, where their own language and culture have been transferred from generation to generation. Of course, deaf people live also in the larger community of hearing people, so it can be said that the deaf community is a bilingual/bicultural society, as are other linguistic minority societies. Baker and Cokely (1980) named this perspective on deaf people and children as a ‘socio-cultural’ one, in contrast with a ‘pathological’ view of deafness which has prevailed in deaf education, where the mono-lingual/mono-cultural principle is forced (Lane, 1984). Evidence from anthropological and ethnographical research on deafness has shown that the former, socio-cultural point of view is needed to understand deeply the lives of deaf children and deaf people, and deaf education in general (Higgins, 1980; Schein, 1989).

The deaf and hard-of-hearing children in this study who were integrated or mainstreamed into the local hearing schools were not fully supported for communication and academic activities. Therefore, a great numbers of those children were reported to be academically delayed. Some of the children had psychological problems before their return to the school for the deaf at the middle or high school level (Torigoe, 2001).

In Japan, the school counselors have been employed by the government in the public middle schools since 1995, though this employment has not been applied to the special schools for the disabled. The pioneering work of this author as a school counselor at the school for the deaf is important to investigate the need for supporting deaf children psychologically.

Method

School

The school for the deaf in this study was a typical middle-sized public deaf school, made up of a preschool program, primary, middle, and high school level programs, and a post secondary program. The total number of children enrolled was around 70, more than half of which were in the preschool and high school level programs. About half of the pupils enrolled in the high school level program had experienced enrollment in the local primary and/or middle schools. The education policy of the local primary and middle school was to educate deaf children by the aural-oral method,
though some teachers at the high school level and post secondary programs used some sort of signing sporadically for communication and instruction.

**Procedures**

The author visited this school once or twice a month, except during the long vacations, for 5 years. The main role as a counselor was the same as the school counselors in general: to do counseling with children and their parents, to do consultation with teachers, and in addition, to sometimes give lectures to teachers or parents groups. The counseling office was located in the school nurse’s room, where children with some problems often came and there was easy contact with those children. The school nurse and the classroom teachers made suggestions to children with problems and to their parents to make contact with the school counselor.

**Results**

**Activities as a school counselor**

The number of the days in visits to this school amounted to 43 days. The counseling and consultation sessions amounted to 104, of which 26 were counseling with children. 16 sessions were counseling with parents, and 62 sessions were consulting with teachers. The average number of sessions for each child counseled or consulted was 2.4 (the range is one to 13). As for the age of the children involved, 83 were high school level, 16 were primary school level, 3 were preschool, and 2 were middle school level. It should be noted here that most of the high school level students who got involved in counseling or consultation had experienced integration into the local hearing schools. Below are narratives of two such cases which were typical of deaf high school students in Japan.

**The descriptions of typical counseling cases**

**Case A**

A female high school student in the third level, named A, came to the nurse’s room one day near her graduation. She said that she could not sleep well when she was thinking about her work after graduation. She had just received a letter of employment from a company where she would like to work after graduation. She was sometimes overcome by uneasiness that she could not succeed in that company. One of the reasons, she said, was that she could not answer the oral examination of the company well without the
aid of interpreter, though she succeeded in that examination. She knew that she would become the only deaf person in that company. At last she said “I am afraid of hearing people.” She always used speech only, because she believed she could express her feelings very well with speech, though she could also sign. Speech with signing was used for counseling.

She discussed her anxiety and her feeling toward hearing people and her experiences with hearing people. She was the only deaf person in her family. When she was detected to be deaf, she was enrolled in the preschool program of this school. She trained and trained orally in the program and, after school, trained once again at home by her mother. Then she enrolled in the local hearing primary school, where she learned some subjects, such as gymnastics, music, social science, in the mainstreamed class, and other subjects, such as language and mathematics, in the self-contained hard-of-hearing class. There was no special support, such as note-taking or sign language interpretation, while in the mainstreamed class. She always did her best to keep up with the classmates and the classroom activities.

She then entered a local middle school, where she was bullied very often by hearing peers. As a result, she came back to the school for the deaf at the high school level. When bullied, she was not supported by parents and teachers, who always told her just to “do your best”. She seemed to have left behind or suppressed the feelings which she experienced when bullied. She was encouraged to talk about those experiences and feelings as concretely as possible, but could not do so sufficiently. She had some difficulty in facing and translating her feelings with ‘language’. ‘Language’ which is not just the vocabulary and grammar of the given language, but it is the use of language to evaluate and understand problems socially and psychologically. She could not express her feelings while bullied, just saying that she ‘did her best’ as the teachers and parents always told her. When she talked about her feelings when working in the future company, she just said that she would ‘do her best’.

She could speak well orally, but her speech seemed to be just for unidirectional communication, not enough for bidirectional communication or for thinking deeply or reflecting on herself with ‘language’. This seemed to be the result of her little experience of deep and vital bidirectional communication until returning to the deaf school. As for her signed language, she told me that she was very excited when she met other deaf peers and
that she had begun to learn the signed language. Her communication skills seemed to have developed greatly during the three years at the deaf school, but was still not sufficient to understand her experiences with 'language'. She continued her counseling until her graduation, and was given information concerning deaf adult groups, and the deaf community for contact and support.

Case B

B was a male high school first level student. The female teacher came to the nurse's room to ask for a consultation with her student. B often abruptly lost his temper in the classroom, and subsequently directed his anger to the teacher, peers, and/or objects. For example, he rushed close to and glared fiercely at the teacher, and threw away a chair or a desk. Sometimes he locked himself in an empty room for an hour or so. He looked very violent and rough. However, it should be noted that he had not injured others thus far. The teacher was often afraid of his actions, but always tried to understand him. When he was calm, he told her that he could not control his anger and behavior when he lost his temper.

His mother also came to the nurse's room for counseling. She stated that she could not believe that her son often lost his temper and seriously misbehaved in the classroom. She said that he was very calm at home and that she had not seen those kinds of behaviors there. She felt that the problem was not in him but in the school. He used speech well at home and no one in the family used sign language, though they knew that B used the sign language with his peers at school. Mother said that she could communicate fully with him without sign language.

After he was found to be deaf, B enrolled in the preschool program in which he was trained orally and his mother also devoted herself to training her son at home. At the local primary school, he did not get any support for learning and communication in the mainstreamed classroom, and, in the end, he could not keep up with his hearing peers academically, though he got some support individually in the self-contained classroom. In addition, he often got bullied by hearing peers. Consequently he came back to the deaf school because he failed in the entrance examination of the mainstreamed high school.

At the integrated period at the primary and middle schools he did not experience deep communication with others. At the self-contained...
classroom, there were no classmates, but only his teacher. At the mainstreamed classroom, there was no support for him to communicate with classmates. After entering the deaf school, his communication environment was drastically changed, having many class-mates who were fluent in sign language. Not all but some teachers were also good at signing.

It would be possible that the current trouble occurred because deep communication began to take place between him and his classmates. The communication contents may have become too complex for him to manage, and he tried to manage this situation by losing his temper or by escaping to an empty room.

At home, there was no rich environment for communication between him and other family members. According to his mother, he could speak and made himself understood with speech at home, but the contents were very simple and that their communication was very superficial. Even the decision to enter the deaf high school was made by his parents, not B, because his mother said it was difficult to discuss it with him.

Consultation was given to support the classroom teacher and to encourage the teacher to continue to talk with B as deliberately as possible. In the classroom, B began to express his feelings by using ‘language’ little by little. In connecting with language, the incidents of losing his temper also decreased gradually.

Discussion

As school counseling is still a relatively new profession in Japan, this paper describes the attempt of school counseling activities in an oral school for the deaf from the socio-cultural point of view. In particular, the focus is on two cases of high school level students who had the experience of integration into hearing primary and middle schools. Both were suffering from psychological troubles. In one case, symptoms appeared on the body, that is, she felt uneasiness and could not sleep well, and in the other case symptoms appeared in the behaviors, that is, he lost his temper and expressed outrageous behaviors.

Those symptoms seemed to have been caused by miscommunication, and developmentally by the lack of experience of deep communication with others. In these two cases, the students had been trained orally and could
communicate somehow with others through speech, but their communication had usually been unidirectional, and superficial. Therefore, they seemed to have not developed fully ‘a language’ with which they interacted deeply with others and with which they were able to reflect on themselves (Vygotsky, 1929; Okamoto, 1985; Torigoe, 2001). In order to support them psychologically, they need to experience deep and vital interaction with others.

The school counselor would play an additional role in this school for the deaf. As described above, the mono-lingual mono-cultural point of view had spread over the classroom and school system, despite the fact that deaf people really live in the bilingual bicultural situation and deaf children would develop more fully under that situation. From a mono-lingual mono-cultural point of view, the teachers of oral deaf schools are reluctant to use signing, even signing with speech. However, for counselors the most valued activity at school is, above all, to communicate fully with the clients, sometimes with only speech, sometimes signing with speech, and sometimes signing without speech. This set the counseling approach to the students different from the teachers’ approach. Thus a model of different values in the classroom and in the school at large might facilitate a change in the situation and create a more flexible and adaptable environment for the students. This activity, or modeling, as a counselor at the school for the deaf was the first one in Japan and pioneering in nature. There is a need for further practice of this kind to draw more general conclusions.

This research was supported in part by Grants-in-Aid (No.16530455) for Scientific Research from the Japan Society for the Promotion of Science, 2004-2005.

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