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Development of Social Learning Program for Students in Undergraduate Deaf Rehabilitation Program

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Abstract

Service-learning models have long since provided students the opportunities to connect with the community they will serve upon graduation. Valley-ICAN (Independent, Confident, Activities, Network) was developed to supplement a capstone practicum requirement for an undergraduate rehabilitation program with a concentration in services to individuals who are deaf or hard of hearing and to help reinforce the curriculum, by connecting the students to the deaf community and the service providers. This article describes the program and its benefits to the students and the community.

Keywords: rehabilitation, practicum, education, service, learning

Training students to be civic-minded and connected to their communities is an important goal of rehabilitation counselor programs (Evenson & Holloway, 2000; Mpofu, 2004, 2005). One method for assisting in this goal is service learning. Service learning has been in use since the early 1900s. John Dewey and William Kirkpatrick are credited with introducing the idea of adding service-learning experiences to curriculum in order to enhance outcomes for students (Conrad & Hedin, 1991).

Over the years, the use of service learning in counselor education programs has steadily increased (Barbee, Scherer, & Combs, 2003). Fields such as business, education, nursing, occupational therapy, physical therapy, and school counseling have also used service learning as part of their curriculum (Arman & Scherer, 2002; Hamm, Dowell, & Houck, 1998; Jorge, 2006; Lashley, 2007; Rehling, 2000). This model is not limited to the United States. Other countries welcome service-learning techniques offered by schools in the United States to serve needs within their countries (Pechak & Thompson, 2009). In addition, literature discusses new interest in students from Germany and Hong Kong engaging in service learning (Baltes & Seifert, 2010; Chung, 2001). This paper describes the development and goals of one such service-learning program for students in an undergraduate Rehabilitation for Individuals who are Deaf or Hard of Hearing (Deaf Rehab) program.
The program, Valley-ICAN (Independent, Confident, Activities, Nnetwork), focuses on the students' experiential activities towards the deaf population in Rio Grande Valley, Texas, and was developed to provide both hands-on experiences while doing good for the community.

**Development of Valley-ICAN**

The Deaf Rehab concentration at the university intentionally limited its number to approximately 15 students because of the practicum requirement. Although local service providers (federal, state, or local) are very generous with allowing students to observe and participate in practicum placements, there is a limited number of community placements that focus on people who are deaf or hard of hearing. There existed a need to identify needed services in which students could participate. Various service providers gave guest lecturers for the students to help fill a gap in the students' experiences within the community. One such guest lecturer was the Deafness Outreach Coordinator of the Communication Access Ability Group (CAAG).

Discussions between the university coordinator and the CAAG representative lead to the identification of the issues each program faced. The university program faced a limited number of volunteer or practicum placements while the CAAG experienced an overflow of community needs. There has been far greater need in the community than the local agencies have been able to provide for. Some of the needs simply do not fall in the realm of provided services from the agencies and there is a shortage of interpreters precludes the individuals from participating. Discussions continued and formed the program outline addressing the (a) goals for the program, (b) leadership roles, (c) goals for the students, (d) program participation, and (e) service-needs identification.

**Goals for the program.** The overarching goals for the program include (a) identify community needs, (b) manage volunteer resources, (d) direct volunteers for effective outcomes, (e) teach students problem-solving skills, (f) expose students to professional meetings, and (g) develop resource library. All of these goals will be explained in more detail in this paper.

**Leadership roles.** There are two people who play key roles in the success of this program: the professor and the CAAG representative. The university professor is involved in identifying community needs, mentoring the students through the program, evaluating the student's progress, and providing
feedback. The CAAG representative is also involved in the identification of community needs and in providing individual referrals and feedback to the students during meetings.

Both parties are present at the meetings where the students provide reports on their activities. It is at these meetings that the majority of the advice and feedback is provided to the student groups. The students also meet with the professor individually for one-on-one feedback and to address any concerns which arise in the program.

**Goals for students.** In addition to identifying the leadership roles as a programmatic goal, the students were identified early in the development stage. The main goals for the students in this program are (a) learning the curriculum, (b) professional networking, (c) experiencing advocacy for others, (d) involvement in the Deaf community and (e) obtaining employment or entering a graduate program.

**Learning the curriculum.** The ultimate goal of this program is to reinforce the curriculum. The students are provided with the opportunity to experience the curriculum in the field. For example, they may be exposed to case management techniques, be provided experience with explaining the ADA to the community, expand their signing skills, and be exposed to any number of experiences directly related the rehabilitation curriculum. In an example, the students were able to meet with a person who lost their hearing due to ototoxic medication used to treat cancer. This experience brought forward an ototoxic lecture, a discussion of the medical aspects of disability, and lectures regarding the psychosocial aspects of deafness in one person's life. The students were also exposed to and assisted in the search for appropriate community resources for this individual. They were able to see the connection of multiple lessons in an individual's life. In addition to using critical thinking skills this activity provided networking opportunities with a variety of local service providers.

In addition to learning the curriculum, students participate in professional meetings and learn the skills necessary for attending such meetings. The students are exposed to meeting agendas, minutes, and the basics of Robert's Rules of Order (Robert, Evans, Honemann, & Blach, 2004). For many students, this is the first opportunity to participate in such structured meetings and to understand the etiquette of meeting participation which they will need upon their graduation.
**Professional networking.** Throughout the time they participate in the program, the students have the opportunity to network with other professionals in the community. Their contact with the community can be obtained in a range of ways. One way, is for the professor and the CAAG representative to set up initial contacts between members of the community and the students such as participation in transition fairs for the Regional Schools for the Deaf. Several agencies and service providers usually attend these functions. Another way, is advising the student of individuals they need to contact to meet their project needs. A third way, is for the students to evaluate their situation and make a determination on who is the appropriate party from whom they can obtain the information or services need to reach their goal. The professor intentionally guides the students through the first two scenarios in order for the third to occur. One goal of the networking experience is for the students to develop the critical-thinking skills and self-confidence necessary to seek out new networking opportunities. This system appears to be successful as evident by the types of jobs which were created for students in the community and the existing positions they have obtained.

**Experiencing advocacy for others.** Through this project, the students have the opportunity to experience advocacy for others. Some of the students participated in helping an individual with deafness to learn how to read. Others participated in helping another deaf person to learn basic manual communication skills. Another group of students assisted with GED training for a group of people who were deaf. In all of these situations the students were able to see progress in the individuals they were working with and experienced first hand the excitement that an individual experiences when reaching a goal. In this way, they developed a greater understanding of the meaning of advocacy.

In addition to the individual advocacy experiences, there were opportunities for groups of students to experience advocacy through community education. These students were involved in seeking opportunities to educate public services organizations and private businesses regarding etiquette for working with people who are deaf or hard of hearing. They explained material learned from the curriculum including their classes of Deaf culture, assistive technology/audiology, policy, and independent living. In this situation, they experienced advocating for the Deaf community through the general hearing community. This opened up opportunities for the hearing population to ask questions in a safe environment. The students were also able to teach basic signs such as “May I help you?” “How can I help you?” and to provide an ASL
signing sheet for very basic communication. They experienced advocating for others through this buy the overwhelming majority of people involved stating they are going to take ASL classes. As part of their advocacy experience for the deaf, the students provided information on local ASL classes. The information included classes from the local university, community college, independent living center, and informal groups participating in activities such as Deaf Coffee Chat and sports leagues within the Deaf community.

**Involvement in the deaf community.** The students may be tangentially involved with the Deaf community as part of the program. However, when being part of the Valley-ICAN they have direct access to individuals in the community and in most cases the families of these individuals. Students experience firsthand the issues faced by this population. They are able to interact with them, learn their life stories, and gain a deeper appreciation for the struggles they face in areas such as interpreter shortage, limited resources resulting in limited opportunities for advancement in career choices, and functional limitation of hearing loss. Through the involvement with the targeted individuals the students were able to meet other people who are deaf through suggested activities of the Deaf community, such as deaf bowling nights, softball, basketball and other activities where the community meets to socialize. This greatly increased the understanding of deaf culture by the students. Students in turn are able to demonstrate this knowledge to perspective employers.

**Obtaining employment or entering graduate programs.** Undoubtedly, seeking employment at this time is difficult. The country is in a recession and jobs seem to be scarce (Bartsch, 2009; Clark & Nakata, 2006). Valley-ICAN uses the students’ own enthusiasm towards their goals to make connections with employers. The career goal of Regional Counselors for the Deaf (RCD) as a Vocational Rehabilitation Counselor (VRC) in the state/federal vocational rehabilitation program for the students is the priority of the program. However, in order to become a VRC in the state one must obtain a Masters in Rehabilitation Counseling. Although this is an undergraduate program, the students who graduate from it are able to compete for VRC positions within the state/federal VR program. Because the students are well prepared for the master’s program many choose to pursue the degree full time. Some receive Rehabilitation Services Administration (RSA) Long Term Training grant scholarships for the masters program and others use their community connections to secure part time or full time employment while finishing their master’s degree. The outcomes for the first group of students...
were rather impressive. Of the 19 students participating in the program, 15 were accepted into the masters of rehabilitation counseling program. Two students accepted a VRC position with the state/federal VR program out of the area and is working on a masters’ degree on line. One graduate decided to take further undergraduate courses and apply for an Occupational Therapy program at the same institution. One made connections with a local cochlear implant surgeon during the Valley-ICAN community outreach activities. The student’s knowledge of the curriculum and community outreach abilities was impressive enough for the surgeon to create a new position. A local service provider created a Deaf Specialist position for another student. Two students are working as itinerate teachers for the local regional school for the deaf. They are continuing their education and certification through the state regional service center. Both were accepted into the masters program but they deferred entrance for one year to become established in their positions. Of the remaining students three were selected and are receiving an RSA graduate scholarship. These scholarships are very competitive: Only eight students received the awards in a pool of over 50 applicants.

Program participation. Any current student in the Deaf Rehabilitation concentration and former Deaf Rehabilitation student in the graduate program is eligible to participate. The students in the Clinical Topics class were selected to be the introductory class of the project. This class takes place in the fall semester and requires a field-based clinical study. Part of the requirement for the class is to give a 30-minute presentation on what they have learned during their activities and the supporting documents are given to each student. An additional packet is given to the CAAG representative to be filed in the clearing house for future reference for anyone seeking information on the topic. For example, students interested in mental health and services for the Deaf would gather information regarding the service, availability, how to obtain employment, and who to contact for more information. Of the goal of the class is for each student to secure a practicum placement by the end of the semester.

The course following Clinical Topics is Practicum which takes place in the spring semester. It is in this capstone course where the bulk of the activities and service learning occurs. The meetings that will be discussed later in this paper take place in the context of this course. As with most practicum classes there is a practicum placement requirement. However, in the Deaf Rehabilitation practicum course due to limited number of practicum sites serving individuals who are deaf or hard of hearing, the students are able
to divide the number of hours required for successful completion of the class. The students must have an approved practicum site but are allowed to count their Valley-ICAN hours toward the total. This allows a greater number of students to experience both the practicum site since the site is not overwhelmed, and community service learning.

**Service-needs identification.** Service request can come from various people in the community, agencies, students, or through the CAAG representative or the professor. Once the professor and CAAG representative identify a list of community needs, the needs are evaluated to see if the students will benefit from participation in the activities, that is whether the activities support the curriculum. In addition, the professor or the representative determines which broad category the activities will fit into, whether they will be classified as one-on-one, community education, or research). After the leadership has determined appropriate activities, a meeting is held with all of the students where the community needs are listed and discussed. The professor intentionally refrains from prioritizing the issues so the students will take ownership of the issues and become more involved in volunteering. In order to not overwhelm the students they are limited to two activities of interest (see Figure 1).

![Diagram](https://repository.wcsu.edu/jadara/vol44/iss3/1)

**Figure 1: Yearly Process of Valley-ICAN**

**Individual.** The individual needs refer to needs for which one person is the intended recipient. The student volunteers meet with the individual and all involved, they schedule convenient for both parties one-on-one time with
the individual to ensure ongoing progress, and pay attention to the goals of that person. The individuals receive one-on-one attention from a group of four to five students. For example, in the past, individual needs included sign language tutoring, reading tutoring, and GED tutoring.

**Community education.** During the Valley-ICAN meetings the students discuss community issues which derive from their experience and their understanding of the curriculum. The professor monitors the discussion of those issues that are perceived as needing attention in the community since they relate to social justice for individuals who are Deaf or hard of hearing. The group needs were community based such as ADA, transition, and addiction committees. Each provided community education on their topic.

**Research.** Issues related to the clarification of laws fall in the research group. When students are asked questions from the community, various means of information gathering are used to form answers. The professor reviews the answers and provides feedback. If the answer is satisfactory then the students report the results to the person or entity who asked the question. Most questions revolve around interpreting issues. These activities hone the information retrieval skills and provide another opportunity to the students to experience advocacy and networking.

**Positive Outcomes**

Although positive outcomes for the recipients of the services and the students have been realized, outcomes including the skill sets learned, the number of presentations given, the number and types of employment the graduates receive, the number of students going into graduate programs to further the education and become VRC for Deaf people and the outcomes of constructs such as attitudes towards the deaf population have not yet been measured in this program. The program is now in the process of obtaining approval for a pretest/posttest research project in which the students involved will be administered a survey measuring their attitudes towards people who are deaf.

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References


Reliability and Validity of the Adapted COPE Scale with Deaf College Students

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Abstract
The purpose of the current study was to investigate the reliability and validity of the Adapted Coping Operations Preference Enquiry (COPE) Scale with deaf college students. The Adapted COPE identifies 15 strategies for managing stressors. 117 deaf college students from Gallaudet University, between the ages of 18 and 25, participated in the present study. When used with this sample, the majority of the Adapted COPE subscales evidenced high or moderate internal consistency reliability, except for the Mental Disengagement and Active Coping subscales. To investigate structural vahdity, principle component analysis was conducted utilizing quartimax rotation. Initial analyses retained 17 factors and failed to replicate the intended subscale structure of the measure. Post-hoc t-tests indicated that responses to the Original COPE by hearing participants and the Adapted COPE by deaf participants were largely similar, except for the Substance Use subscale, with significantly higher mean scores in the deaf sample. This suggests that the psychometric analyses of the original COPE scale indicate a need for additional restructuring of the measure.

Keywords: coping, psychometrics, deaf

Coping and its relationship to various psychological processes, personality characteristics, and physical and mental health outcomes has been extensively studied (e.g., Epstein, 1992; Herrald & Tomaka, 2002; Plante, Yancey, Sherman, & Muertin, 2000). Numerous coping strategies have been shown to be conducive to one's ability to cope with life-changing events. Using humor as a coping strategy, for instance, has been linked to rapid cardiovascular recovery and increased immunity (Herald & Tomaka, 2002). Also, utilizing one consistent form of coping has been shown to be more effective than vacillating between multiple coping strategies (Fauerbach, Lawrence, Bryant, & Smith, 2002). In a study of burn victims, those who alternated between venting and blocking emotions were more likely to have poorer health outcomes and depression than those who maintained one coping strategy (Fauerbach et. al., 2002).

Coping research has also investigated psychological growth in potentially traumatic experiences, such as limb amputation and burning incidents (Fauerbach et. al., 2002; Oaksford, Frude, & Cuddihy, 2005). Those who utilized coping strategies, such as support seeking, humor, and religion were...
able to adapt to the trauma, had a greater commitment to personal goals and greater well-being, and exhibited lower levels of psychological distress (Ellison, 1991; Oaksford, Frude, & Cuddihy, 2005; Plante et al., 2000; Ross, 1990).

An individual's coping strategy tends to remain consistent from one situation to the next (Lazarus, Gruen, & DeLongis, 1986). It is therefore important to measure current coping behavior to predict how individuals will cope with future events. Such measurement can also help to determine the most effective coping strategies for unique populations and inform the work that professionals do with these populations.

Coping and Mental Health in Deaf Individuals

"Deaf" is a label that refers to a heterogeneous mix of individuals with varying levels of hearing loss, age of onset, and etiologies (Gallaudet National Summary, 2008). In terms of identity, some deaf individuals identify as culturally Deaf, defining themselves as members of the Deaf culture through a unifying language (American Sign Language) and set of values (Lane, Hoffmeister, & Bahan, 1996). These culturally Deaf individuals identify themselves as a cultural and linguistic minority rather than as a population with a disability (Lane, Hoffmeister, & Bahan, 1996). Other individuals identify as medically deaf rather than culturally Deaf, hard of hearing, or bicultural (Leigh, 2009). It is important to consider the diversity in the deaf population when drawing generalizations from research with deaf individuals.

Research on coping strategies in a deaf population has been limited. Such research is greatly needed, since deaf individuals not only face everyday stressors that hearing people face, but also additional stressors related to being deaf in a hearing society. These stressors may include inaccessibility of information, isolation due to communication barriers, and stress related to membership in a cultural and linguistic minority group (Jones, Ouellette, & Kang, 2006). For instance, deaf individuals may face underemployment or unemployment due to communication barriers and limited options for accessible job training (Long, 1992; Schirmer, 2001). Deaf adults may face low socioeconomic status and have "low status" jobs as a consequence, causing additional stressors (Cohen & Williamson, 1998, as cited in Jones, Ouellette, & Kang, 2006).
Deaf adults have reported feelings of isolation due to limitations in communication, missing information, and a sense of being different (Bain, Scott, & Steinberg, 2004; Oliva, 2004). Feelings of isolation depend heavily on communication preferences of deaf individuals and their corresponding environment. Charlson, Strong, and Gold (1992) found that deaf students in mainstream schools were more likely to feel disconnected from teachers and peers. This study also found that in a residential school, deaf students had improved accessibility to education and greater potential for social relationships with other deaf peers. Yet, students at residential settings were more likely to feel disconnected from their families if they lived on campus during the week. The connections that deaf individuals develop as children through school, peer groups, and family, as well as the language they acquire, impact the support systems they utilize later in life (Tidball, 1990).

Coping can be categorized as problem-focused coping (e.g. planning, seeking instrumental social support) and emotion-focused coping (e.g. acceptance, positive reinterpretation, seeking emotional social support) (Carver, Scheier, & Weintraub, 1989; Lazarus & Folkman, 1984). Problem-focused coping strategies that deaf people may utilize to manage these unique stressors include self-advocacy, improving speech-reading and speaking skills, modification of the environment to ensure clear communication, use of assistive listening devices, use of sign language, involvement of activities, building relationships with deaf peers, and ensuring workplace accommodations were in place (Bain, Scott, & Steinberg, 2004; Rogers, Muir, & Evenson, 2003). Emotion-focused strategies specific to deaf stressors include developing a positive self-image, denying problems, and maintaining contact with deaf peers, a good sense of humor, a sense of caring, and supportive family environment (Charlson, Strong, & Gold, 1992; Rogers, Muir, & Evenson, 2003).

A strong Deaf identity has also been shown to act as a buffer against feelings of isolation and worthlessness (Charlson, Strong, & Gold, 1992; Tidball, 1990). The additional stressors that deaf individuals must manage in their lifetime may have a positive effect later in life. Deaf senior citizens have been shown to approach the retirement process with less stress than hearing peers (Tidball, 1990). One reason for this may be that deaf senior citizens have already developed effective coping strategies in response to greater stress in their lifetime (Tidball, 1990). Overall, deaf adults who identify with the Deaf community and spend much of their time with other deaf people often have higher self-esteem than those who do not (Bat-
Self-esteem has been found to be a powerful mediator in coping ability, especially in deaf individuals (Rogers, Muir, & Evenson, 2003).

Assessing Coping Skills in Deaf Individuals

There has been little systematic investigation of stress and coping in deaf individuals. Kordus (1998) used the COPE Scale, a popular measure of coping (Carver, Scheier, & Weintraub, 1989) (see below for a description of the scale) to examine coping effectiveness in deaf individuals with HIV/AIDS. She adapted this measure to be administered to a deaf sample, but did not test it for reliability and validity with deaf individuals. Adams (2000) investigated the reliability and validity of a measure called the Problem-Focus Style of Coping (PF-SOC) with deaf individuals. Adams found this to be a partially valid and reliable instrument to be used with deaf people. Jambor and Elliott (2005) investigated self-esteem and coping strategies among deaf college students using a self-report questionnaire that included deafness-related factors, identification with the Deaf world, self-esteem, coping strategies, and demographic variables. The authors constructed this questionnaire but did not examine its reliability or validity.

Considering this limited research, it is clear that research investigating the measures that assess stress and coping in deaf individuals is necessary, particularly when trying to assess their resilience in view of life stresses. Such measures must be relevant for the unique cultural, linguistic, and accessibility needs of a deaf population. Such measures can lead to identifying those individuals who can benefit from positive coping strategies, which may be taught. The COPE, which was used in the Kordus (1998) study, is one such measure with potential for use in this population if its reliability and validity can be demonstrated.

Reliability and Validity of the Original COPE Scale

The original COPE scale is a broad measure of coping strategies that people may use at one time or another, including problem-focused and emotion-focused forms of coping and other forms of coping that may be deemed as adaptive or maladaptive. It contains 60 items comprising 15 subscales, with four items per subscale. These subscales are labeled as follows: Positive Interpretation and Growth, Mental Disengagement, Focus on and Venting Emotions, Use of Instrumental Social Support, Active
Coping, Denial, Religious Coping, Humor, Behavioral Disengagement, Restraint, Use of Emotional Social Support, Substance Use (also labeled as Alcohol/Drug Use), Acceptance, Suppression of Competing Activities, and Planning. Participants are instructed to rate on a Likert scale how often they engage in each item while under stress: 1 = "I usually don't do this at all;" 2 = "I usually do this a little bit;" 3 = "I usually do this a medium amount;" and 4 = "I usually do this a lot." This measure takes approximately 5-10 minutes to administer.

The researchers who investigated the original COPE Scale for internal consistency found that the Cronbach's alpha reliability coefficients for each scale were greater than .6 (an acceptable level) with one exception (Carver, Scheier, &c Weintraub, 1989). Test-retest correlations also suggested that the COPE Scale was relatively stable. Additionally, an exploratory factor analysis of the original COPE scale yielded 14 factors with item loadings on each factor ranging from .19 to .95. The weakest items of this factor analysis in the Carver, Scheier, and Weintraub (1989) study occurred in Positive Reinterpretation and Growth (.19) and Mental Disengagement (.23), while the strongest loadings occurred within the Turning to Religion factor (.88 and .95). The 15th factor, Humor, was added to the COPE following a study by Carver, Scheier, and Weintraub (1989), but was never tested for reliability and validity.

As a further assessment of the reliability of the COPE, correlations among the subscales were computed. Correlations were all low (ranging from .00 to .45), indicating distinct subscales, except for Active Coping, which correlated with Planning (.67), and Seeking Instrumental Social Support, which was correlated with Seeking Emotional Social Support (.69) (Carver, Scheier, &c Weintraub, 1989).

To determine convergent and discriminant validity, the original COPE scales were correlated with selected personality measures (Carver, Scheier, &c Weintraub, 1989). The researchers reported that the pattern of associations obtained generally produced the hypothesized results. For instance, Active Coping and Planning were significantly correlated with several conceptually related personality qualities, such as optimism and self-esteem. Divergent validity was also demonstrated by negative correlations between the COPE scales and theoretically opposing personality measures, such as behavioral disengagement and control.
Based on their psychometric findings described above, Carver, Scheier, and Weintraub (1989) concluded that the original COPE was sufficiently reliable and valid for the investigation of coping skills.

**Purpose of the Study**

The purpose of the current study was to investigate the reliability and validity of an adapted version of the COPE scale when used with deaf college students. In accordance with the original study by Carver, Scheier, and Weintraub (1989), reliability of the Adapted COPE was investigated utilizing measures of internal consistency. Validity within the current sample was investigated via exploratory factor analysis to determine whether items loaded on their intended subscales.

**Method**

**Participants**

Students at Gallaudet University who identified themselves as culturally Deaf, deaf, or hard of hearing were invited to participate in the current study. Participants were between the ages of 18 and 25, without additional physical or mental disabilities. The age limit was used as an inclusion criterion to align with the reliability and validity study of the original COPE scale by Carver, Scheier, and Weintraub (1989).

According to conventional standards of factor analysis, sample size should be determined based on the number of items on the questionnaire (Tabachnick & Fidell, 1996). Tabachnick and Fidell (1996) recommend that 2 to 20 subjects should be recruited per questionnaire item. The researchers opted to utilize Tabachnick and Fidell's (1996) recommendation for number of participants in order to maintain a smaller, homogenous sample with strong internal validity. Thus, in order to obtain at least two participants per item, considering a total of 60 items, 120 undergraduate students attending a four-year university for Deaf and hard of hearing students were recruited for the current study.

Three participants were disqualified from the study because they exceeded the age limit. This resulted in a total of 117 participants: 22 males and 95 females. The mean age was 20.75 years, with a range of 18 to 25 years. Additional participant characteristics are listed in Table 1.
Table 1. Demographic characteristics of the sample

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<tr>
<th>Demographic Characteristics</th>
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<tr>
<td>Before Age 2</td>
<td>16.6%</td>
</tr>
<tr>
<td>After Age 2</td>
<td>14.2%</td>
</tr>
<tr>
<td>Preferred Communication Mode</td>
<td></td>
</tr>
<tr>
<td>American Sign Language</td>
<td>73.3%</td>
</tr>
<tr>
<td>Pidgin Sign Language</td>
<td>5.0%</td>
</tr>
<tr>
<td>Spoken English</td>
<td>3.3%</td>
</tr>
<tr>
<td>Total Communication</td>
<td>2.5%</td>
</tr>
<tr>
<td>Simultaneous Communication</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>5%</td>
</tr>
</tbody>
</table>

Measures

The Adapted Coping Operations Preference Enquiry (COPE). The COPE scale was first revised for deaf readers by Kordus (1998), who simplified lengthy English statements to accommodate deaf participants (Kelly & Barac-Cikoja, 2007). Kordus also revised phrases that included figurative language, such as changing "36. I kid around about it" to "36. I joke around about it." Considering that for culturally Deaf individuals, the primary language is American Sign Language, English skills can and do vary widely (Moores, 2001). For this reason, measures are reviewed for English clarity and simplicity, and adapted as needed to ensure that deaf readers understand the items. These adapted measures need to be assessed for reliability, and in fact such adapted measures have demonstrated acceptable internal consistencies using deaf college student samples (Leigh & Anthony-Tolbert, 2001).
With permission from the original researcher, Dr. Charles Carver (personal communication, September 20, 2006), the current study made several additional revisions in consultation with an English professor at a deaf university and a deaf research advisor, thus resulting in the Adapted COPE Scale. These changes were made in order to create more direct phrases and statements that would be more readily understood by a deaf population while maintaining the overall meaning of the original questionnaire.

**Demographic Questionnaire.** A brief 19-item demographic questionnaire that assessed variables such as age, gender, educational background, ethnic background, degree of hearing loss, hearing status, and preferred mode of communication was also administered to gain background information. Additional items also included family background, educational background, and mental health background.

**Procedures**

After obtaining IRB approval and permission to adapt the COPE scale as originally developed by Carver, Scheier, and Weintraub (1989), participants were recruited with flyers posted on campus and information sent via campus-wide email. Following email correspondence, participants were scheduled to meet the investigator or research assistant who matched the communication styles of the participants (e.g., American Sign Language, Signed Exact English, Signed English, Simultaneous Communication). They were then informed of the purpose of the study, the procedures involved, and the confidentiality of all information. Participants then completed the brief demographic survey and the Adapted COPE scale. These measures required approximately 30 minutes to complete. Participants were given 10 dollars as compensation.

**Results**

Responses from all questionnaires were entered into the SPSS statistical program. Adapted COPE data were then analyzed for internal consistency and factor structure.

**Descriptive Statistics**

The Adapted COPE identifies various strategies for managing stressors represented by 15 subscales. The possible scores for each subscale ranged
from four to 16. Means and standard deviations are reported in Table 2.

Table 2. Descriptive statistics of Adapted COPE Subscales

<table>
<thead>
<tr>
<th>Subscale</th>
<th>Mean</th>
<th>Standard Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Positive Reinterpretation and Growth</td>
<td>13.50</td>
<td>1.96</td>
</tr>
<tr>
<td>Acceptance</td>
<td>12.16</td>
<td>2.16</td>
</tr>
<tr>
<td>Planning</td>
<td>12.07</td>
<td>2.06</td>
</tr>
<tr>
<td>Use of Instrumental Support</td>
<td>12.06</td>
<td>2.74</td>
</tr>
<tr>
<td>Use of Emotional Social Support</td>
<td>11.90</td>
<td>2.81</td>
</tr>
<tr>
<td>Active Coping</td>
<td>11.47</td>
<td>1.89</td>
</tr>
<tr>
<td>Mental Disengagement</td>
<td>10.67</td>
<td>1.91</td>
</tr>
<tr>
<td>Focus On and Venting of Emotions</td>
<td>10.53</td>
<td>2.51</td>
</tr>
<tr>
<td>Restraint</td>
<td>9.79</td>
<td>2.01</td>
</tr>
<tr>
<td>Suppression of Competing Activities</td>
<td>9.46</td>
<td>2.32</td>
</tr>
<tr>
<td>Humor</td>
<td>9.29</td>
<td>2.96</td>
</tr>
<tr>
<td>Religious Coping</td>
<td>7.57</td>
<td>3.59</td>
</tr>
<tr>
<td>Behavioral Disengagement</td>
<td>7.12</td>
<td>1.91</td>
</tr>
<tr>
<td>Denial</td>
<td>6.54</td>
<td>2.27</td>
</tr>
<tr>
<td>Substance Use</td>
<td>5.85</td>
<td>2.86</td>
</tr>
</tbody>
</table>

Reliability

In order to investigate reliability of the Adapted COPE, the internal consistency of each subscale was computed using Cronbach's alpha. An alpha value of $\geq 0.70$ was considered high and a value of $\geq 0.50$ was considered moderate.

In the current sample, the majority of Adapted COPE subscales evidenced high or moderate internal consistency (see Table 3). Subscales measuring Focus on and Venting of Emotions, Use of Instrumental Social Support, Denial, Religious Coping, Humor, Use of Emotional Social Support, and Substance Use evidenced high internal consistency. Subscales measuring Positive Reinterpretation and Growth, Behavioral Disengagement, Restraint, Acceptance, Suppression of Competing Activities, and Planning evidenced moderate internal consistency.
However, the Mental Disengagement and Active Coping subscales were found to have low internal consistency. Additional analyses were conducted to determine if any particular items from these two subscales significantly contributed to the low levels of internal consistency. This was done in order to provide justification for altering or deleting those particular items for deaf populations. For the Mental Disengagement subscale, internal consistency did not significantly improve with the deletion of any particular item. However, on the Active Coping scale, the deletion of item #25 ("I take additional action to try to get rid of the problem") resulted in an increase in Cronbach's alpha, from .417 to .597.

**Table 3. Internal consistency reliability of the Adapted COPE with a sample of deaf undergraduates**

<table>
<thead>
<tr>
<th>Scale</th>
<th>Cronbach's Alpha</th>
</tr>
</thead>
<tbody>
<tr>
<td>Substance Use</td>
<td>.924**</td>
</tr>
<tr>
<td>Religious Coping</td>
<td>.915**</td>
</tr>
<tr>
<td>Humor</td>
<td>.847**</td>
</tr>
<tr>
<td>Use of Instrumental Support</td>
<td>.800**</td>
</tr>
<tr>
<td>Use of Emotional Social Support</td>
<td>.790**</td>
</tr>
<tr>
<td>Denial</td>
<td>.759**</td>
</tr>
<tr>
<td>Focus On and Venting of Emotions</td>
<td>.734**</td>
</tr>
<tr>
<td>Positive Reinterpretation and Growth</td>
<td>.690*</td>
</tr>
<tr>
<td>Suppression of Competing Activities</td>
<td>.672*</td>
</tr>
<tr>
<td>Acceptance</td>
<td>.645*</td>
</tr>
<tr>
<td>Planning</td>
<td>.617*</td>
</tr>
<tr>
<td>Behavioral Disengagement</td>
<td>.559*</td>
</tr>
<tr>
<td>Restraint</td>
<td>.554*</td>
</tr>
<tr>
<td>Active Coping</td>
<td>.417</td>
</tr>
<tr>
<td>Mental Disengagement</td>
<td>.279</td>
</tr>
</tbody>
</table>

*Note. ** = High internal consistency; * = Moderate internal consistency*

**Factor Structure**

To determine the structural validity of the Adapted COPE scale with a deaf undergraduate sample, exploratory factor analysis was conducted. Principle component analysis was conducted utilizing quartimax rotation, as the subscales were not independent. The initial analysis retained 17 factors,
determined using eigenvalue (Eig=1), variance, and scree plot. These factors accounted for 73.9% of the total variance.

Table 4. Exploratory factor analysis, quartimax rotation – factor loadings for Adapted COPE subscales

<table>
<thead>
<tr>
<th>Factor</th>
<th>Items loading above .40</th>
<th>Intended COPE scale</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>4*, 5, 11, 14*, 21, 23*, 29, 30, 44, 45, 52, 59</td>
<td>Use of instrumental support, Use of emotional support, acceptance, Positive reinterpretation and growth, Active coping</td>
</tr>
<tr>
<td>2</td>
<td>12, 26, 35, 53</td>
<td>Substance use</td>
</tr>
<tr>
<td>3</td>
<td>7, 18, 48, 60</td>
<td>Religious coping</td>
</tr>
<tr>
<td>4</td>
<td>3, 4*, 17, 23*, 28, 34, 46</td>
<td>Focus on venting of emotions, Use of emotional social support, Use of instrumental social support</td>
</tr>
<tr>
<td>5</td>
<td>8, 20, 36, 50</td>
<td>Humor</td>
</tr>
<tr>
<td>6</td>
<td>27, 40, 51, 57</td>
<td>Denial, Behavioral Disengagement</td>
</tr>
<tr>
<td>7</td>
<td>15, 19, 22*, 32, 33, 43, 47</td>
<td>Suppression of competing activities, Planning, Restraint, Mental disengagement, Active coping</td>
</tr>
<tr>
<td>8</td>
<td>10, 22*, 41</td>
<td>Restraint</td>
</tr>
<tr>
<td>9</td>
<td>24, 37, 39°</td>
<td>Behavioral disengagement, Planning</td>
</tr>
<tr>
<td>10</td>
<td>25, 56</td>
<td>Active coping, Planning</td>
</tr>
<tr>
<td>11</td>
<td>54</td>
<td>Acceptance</td>
</tr>
<tr>
<td>12</td>
<td>42, 55</td>
<td>Suppression of competing activities</td>
</tr>
<tr>
<td>13</td>
<td>16</td>
<td>Mental disengagement</td>
</tr>
<tr>
<td>14</td>
<td>2, 37°</td>
<td>Mental disengagement, behavioral disengagement</td>
</tr>
<tr>
<td>15</td>
<td>9</td>
<td>Behavioral disengagement</td>
</tr>
<tr>
<td>16</td>
<td>31</td>
<td>Mental disengagement</td>
</tr>
<tr>
<td>17</td>
<td>13, 14*</td>
<td>Acceptance</td>
</tr>
</tbody>
</table>

Note. * = Item loaded on multiple scales, ° = Negative loading

A rule of thumb for determining if an item loads on a factor is a rotated factor loading of at least .40 (Garson, 2008). Therefore, an item is listed as loading on a factor if its factor loading was .40 or above. Item loadings
onto the 17 factors are listed in Table 4. The Substance Abuse, Religious Coping, and Humor scales each loaded cleanly as in previously studied samples. Instrumental Social Support, Emotional Social Support, Focus on and Venting of Emotions, Restraint, and Denial generally loaded together, but individual items were split among factors. The Positive Reinterpretation and Growth, Mental Disengagement, Active Coping, Behavioral Disengagement, Acceptance, and Planning scales of the COPE did not load together, with items split among the factors.

**Post-hoc analyses**

Post-hoc t-tests were conducted with reliable and valid subscales to assess whether or not there were differences between hearing participants' responses to the Original COPE and the present sample's responses to the Adapted COPE. None of the subscales of the COPE were found to be different between the two populations, except for Substance Use (also known as Alcohol-Drug Use) subscale, $t(119) = 5.96, p < .05$, on which the current sample of deaf participants (mean = 5.85) scored higher than the original hearing participants (mean = 1.38).

**Discussion**

The objective of the current study was to investigate the utility of the Adapted COPE Scale with a sample of deaf undergraduate students. Using a sample of 117 respondents, data were analyzed for internal consistency reliability and structural validity.

**Reliability**

Overall, the subscales of the Adapted COPE scale demonstrated acceptable internal consistency within this sample of deaf undergraduates, with seven of the 15 scales exhibiting Cronbach's alpha values above .70, which reflects high internal consistency. Six of the 15 scales demonstrated moderate internal consistency, exhibiting Cronbach's alpha values above .50. Due to the limited power in conducting research with a small sample size, moderate internal consistency was considered reliable for the purposes of the current study.

While the majority of subscales evidenced reliability within this sample, two did not: Mental Disengagement and Active Coping. This
finding is comparable to the original reliability and validity study, in which these subscales yielded the lowest Cronbach’s alpha values (.45 and .62, respectively) (Carver, Scheier, & Weintraub, 1989). Therefore, the low levels of internal consistency in these subscales are likely due to weaknesses of the original COPE subscales. In fact, the authors of the original COPE study noted that the Mental Disengagement scale was described as a multiple-act criterion, which involves repeated observations of different behaviors, causing expected lower reliability (Fishbein & Ajzen, 1974).

Additionally, it should be noted that two of the subscales (Substance Use and Religious Coping) evidenced Cronbach’s alpha values above .90. Generally speaking, internal consistencies that are this high typically indicate scales that contain redundant items. In other words, the items are too highly correlated and may be querying the identical information. These extremely high internal consistencies suggest that these particular scales may contain unnecessary items that can be deleted in future revisions of the measure.

Although two Adapted COPE subscales evidenced low levels of internal consistency and there was indication of some redundancy, the majority of subscales reliably measure coping behaviors within this sample of deaf undergraduates. To ensure the consistency of all the subscales, further research should be conducted with a larger sample of deaf adults, as well as the general population.

Validity

The current exploratory factor analysis provided little support for the structural validity of the Adapted COPE when used with deaf undergraduates. Of the 17 factors retained, 12 of the intended scales were split across these factors. Only items measuring Substance Use, Religious Coping, and Humor loaded together as the original measure intended. However, as mentioned above, the Substance Use and Religious Coping subscales evidenced internal consistency values that suggested redundancy. Therefore, the items from these intended subscales may be loaded cleanly because they are asking highly overlapping questions.

Additionally, items from several intended subscales loaded onto one combined factor. As can be seen in Table 3, the factors pulled scales into more general categories, such as emotion-focused coping, problem-focused coping, or the less healthy coping skills of venting and disengaging as...
described by the original validity and reliability study (Carver, Scheier, & Weintraub, 1989). For example, items intended to measure Use of Instrumental Social Support and Use of Emotional Social Support loaded on one factor. While the separation of these two types of support is understandable in theory, seeking social support of any type converged during factor analysis of this sample. Interestingly, when the results from the Carver, Scheier, and Weintraub (1989) study were investigated further, it was found that "loadings for seeking social support for instrumental reasons and seeking support for emotional reasons come from a single factor that incorporated both scales" (1989, p. 272). This joint loading also occurred with Active Coping and Planning items, which loaded on one scale. It is not readily apparent why these subscales were not combined into more general subscales after the original psychometric analyses. However, the current data align with the original COPE psychometric analyses, indicating the need to restructure the COPE with fewer, more general subscales for both deaf and hearing populations. As the COPE continues to be used in research studies (C. Carver, personal communication, June 8, 2007), there is a real need to restructure this measure.

In addition to creating more general, comprehensive subscales, a restructuring of the COPE would also lend itself to more effective psychometric analyses. Given that each scale of the Adapted COPE was comprised of only four items, even one item loading on another scale significantly affects the structural validity, as at least three item loadings are required to create a factor. Returning to the original COPE, it was found that five of the subscales (Active Coping, Positive Reinterpretation and Growth, Acceptance, Behavioral Disengagement, and Mental Disengagement) contained items with loadings well below the standard of .40. Additionally, the large number of subscales (15) and relatively small sample size likely affected the current researchers' ability to replicate the structure of the COPE.

With regard to the post-hoc t-tests comparing hearing and deaf participant responses, it is possible that deaf individuals may be more at risk for abusing substances as a coping mechanism. This may be due to educational difficulties, lack of positive deaf role models, communication barriers, lack of appropriate drug education, fewer social supports, and lack of access to drug abuse prevention resources (Guthmann, Sandberg, & Dickinson, 2010; Titus, Schiller, & Guthmann, 2008). These factors may result in differences in the structure of coping strategies between deaf and
hearing groups; however, further research should be conducted in order to understand the factors behind deaf individuals’ use of substances for coping purposes.

Limitations and Future Directions

The current study is limited by the relatively small number of participants which is a result of a small undergraduate cohort from which to recruit. It may be that using the minimum number of participants per item returned factors with poor reliability and contributed to the discrepancies in item loading onto the expected subscales. Even though Tabachnick and Fidell (1996) recommended that two to 20 subjects should be recruited per questionnaire item, as explained in the Participant section, this resulted in a relatively small sample size for computing factor analysis. Tabachnick and Fidell (2007) later recommended 300 cases for computing a factor analysis. However, considering the small recruitment pool, it is often unrealistic to collect a sample of 300 participants while still upholding internal validity. The current data, therefore, provide preliminary information on which future research with larger samples of deaf participants can build.

As stated above, the psychometric analyses of the original COPE scale indicated a need for additional restructuring of the measure. The current results with deaf undergraduates indicate the need for a similar restructuring. Therefore, future research should seek to restructure the COPE scale based on results from exploratory factor analysis, ultimately resulting in a smaller number of scales that more accurately measure general aspects of coping.

While efforts were made to maintain the meaning of the original COPE items, certain items of the Adapted COPE were worded differently and may have impacted the resulting factor structure. Additionally, the samples were not demographically matched, other than that both samples consisted of college students. A larger sample in future research should strive to recruit demographically matched samples. It is important to note that the current sample is comprised of deaf students between the ages of 18 and 25. Therefore, the current data on reliability and validity of the Adapted COPE is likely not generalizable to adult members of the Deaf community above this age range, or deaf individuals who have not pursued higher education. Future research should recruit deaf community members in order to ascertain the internal consistency and structural validity of the Adapted COPE in a more general, community-based sample. By validating all of the subscales...
of the Adapted COPE, researchers can obtain more complete data on deaf individuals’ use of both adaptive and maladaptive coping mechanisms, providing a fuller picture of the experiences and needs of our deaf clients.

Deaf college students constitute a unique sample in that being deaf or hard of hearing may indicate different or additional stressors to cope with on a daily basis. In this way, deaf students may have developed unique coping skills that are not mentioned in the original or Adapted COPE scales. This could make the measures comparatively insensitive and less applicable to deaf people as the measures currently exist, unless aspects of these unique coping skills are incorporated. Future research would do well to investigate the types of stressors that deaf and hard of hearing individuals encounter, and the coping strategies they typically utilize to become resilient. This type of research would better inform the literature regarding how deaf individuals cope in their daily lives.

growth following lower limb amputation.

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References


Gathering Perceptions about Current Mental Health Services and Collecting Ideas for Improved Service Delivery for Persons who are Deaf, Deaf Blind and Hard of Hearing

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Abstract
The authors present a model for obtaining feedback from consumers and therapists about mental health services and outreach strategies from persons who are Deaf, Deaf Blind and Hard of hearing. Program planners from Western Pennsylvania used the focus group as a research tool to generate valid information to advance program development. Nine focus groups were conducted which were comprised of consumers, therapists or family members. Feedback from the focus group has led to the implementation of new services in Western Pennsylvania. Group members reported that the focus group format fostered a spirit of collaboration and community problem-solving.

Keywords: focus groups, deaf, deafblind, hard of hearing

Hearing loss is the sixth most common condition in the non-institutionalized United States population, with a prevalence of 9.35% (Iezzoni, O'Day, Killeen & Harker, 2004). Many consumers with hearing loss have limited access to the public mental health system. Deaf leaders, consumers and professional organizations have advocated for specialized mental health services for consumers who are Deaf. In a position statement from the National Association of the Deaf (2003) "accessible" treatment is defined as providing reasonable accommodations to consumers who are Deaf, Deaf Blind or Hard of hearing. Culturally affirmative treatment is understood as receiving services from ASL fluent clinicians who are trained specifically to work with persons who are Deaf. Various lawsuits have spurred program development of specialized services for the Deaf in states such as Minnesota, Alabama and South Carolina (Gournaris, Hammerdinger & Williams, 2010).

For a variety of reasons, the prevalence of mental health problems is greater among those with hearing loss (McEntee, 1993). However, only about one-fifth of persons with hearing loss are able to access services when they seek
treatment (Pollard, 1994). Few studies have been published that address why consumers who are Deaf do not access services more frequently. Best practices for raising awareness about existing behavioral health services, and community opinions about current services or necessary service improvements which may be more recovery oriented, are little known.

Only a limited number of studies articles exist where consumer opinion has been obtained directly (from persons who self identify as being Deaf) about health services and health care access (Steinberg, Loew & Sullivan, 1999; Steinberg, Barnett, Meador, Wiggins & Zazove, 2006). There are even fewer articles in the literature where the specific needs of persons who self identify as being hard of hearing or DeafBlind are analyzed. (Trychin, 2003; Bailey & Miner, 2010).

We knew that specialized behavioral health services for the deaf are underutilized in our community by all persons who are Deaf, DeafBlind or hard of hearing. In 2005, county behavioral health administrators and service providers who served the Deaf community began to work together with community leaders and consumers on a task force. This task force aimed to begin to address issues related to observed disparities in behavioral health care services that exist for all persons with hearing loss in Western Pennsylvania. Program planners thought that by conducting focus groups with consumers who utilized services in our region, that the task force would be able to gather information to better direct service development and outreach efforts.

In the process of forming focus groups for research purposes, it has been suggested that it is best to compose focus groups of approximately 10 participants. Groups should not be highly different in power, language, status, income, or personal characteristics. It is felt that individuals will tend to censor their ideas if the group is too diverse (Creswell, 1998). To understand the perspectives of different groups of people, Creswell suggests composing multiple focus groups on the same topic.

We aimed to gather consumer input from individuals with hearing loss who utilized either English or American Sign Language. Groups were conducted in whatever language was primary. In this manner, Consumers and therapists could express their ideas and problem solve with others in their native language. We separated the consumer groups based on preferred language choice and accommodations requested. We viewed that these primary choices would translate into distinct issues that would affect health care access.
We created probes (see appendix) that would create a framework for information about best practices for community outreach and generate ideas for improvements on existing services which were needed in our community. A summary of topics include:

1. Access to Health Information
2. Resource Awareness
3. Barriers to Current Treatment
4. Preferred New Services

Methods

Nine focus groups were conducted which were approximately 90 minutes in length. These focus groups were all conducted in a large, Pennsylvania metropolitan area. We recruited participants from outpatient counseling centers, area support groups and community organizations for persons who are Deaf, DeafBlind or hard of hearing. Six focus groups were comprised exclusively of consumers, one group was comprised of therapists who served the population, and two groups were comprised of family members of consumers who received services at area mental health agencies.

Inclusion criteria for the six consumer groups included having moderate to profound hearing loss, a history of receiving mental health care, and a willingness to share prior experiences with the mental health care system. Inclusion criteria for the family groups included having a relative with hearing loss, experience with the mental health system, and a willingness to share those service experiences. Lastly, the inclusion criterion for the specialized service provider focus group was being a mental health counselor who currently provided therapy services to persons with hearing loss.

Thus, focus group participants were separated first by self-identification as consumer, family member or therapist. After these initial separations were made, four of the six consumer groups were constituted based on language preference and preferred accommodations. Because it was presumed that accommodation preference would divide the issues expressed in each focus group and the way that information access and service delivery occurred, groups were organized so that members had similar accommodation requests and language preference.

Two consumer groups were organized where members expressed a language preference for American Sign Language (ASL). Two other consumer groups
were organized where members who are hard of hearing expressed a preference for utilizing spoken English with FM amplification and Communication Access Real-time Translation (CART). CART was performed by an expert stenographer who typed the proceedings of the meetings into phonetic output in real-time English that is displayed on a screen. The FM system used by some group participants is a device that amplifies spoken language for a person who uses an oral mode of communication.

Three groups, including the remaining two consumer groups, were mixed as to the member’s native language. These linguistically mixed groups included the group defined as DeafBlind, the transition age group and the therapist group. These groups were not subdivided by preferred language modality because group members participated regularly in multilingual settings. Two family groups were conducted utilizing spoken English.

Many authors have written about the unique needs of the transition age population. In clinical practice, in our region, there are many young people who are graduating from area schools and have hearing loss or deafness who present with unmet mental health and social service needs. Hence, the authors felt that it was important to conduct at least one transition age group. This population is defined as youths who are not yet self-sufficient, who may be completing high school or aging out of child behavioral health service (Clark & Uhrich, 2009).

For the groups where members requested ASL, the focus groups were conducted by mental health practitioners who were fluent in ASL. A Pennsylvania registered/certified interpreter was used as well for the purposes of recording the group proceedings.

The focus group that was comprised of individuals who identified themselves as being DeafBlind was the most varied in the accommodations that were requested, which by their description were related to the age of onset and severity of their hearing loss. Tactile sign was utilized by about a third of the group; others in the group used FM systems or communicated in ASL.

We collected basic sociodemographic information from focus group participants (see Table I). Focus group facilitators developed a series of probes (see appendix). There were two focus group facilitators, who regularly worked within the Deaf community and with persons who are hard of hearing or DeafBlind. Certified interpreters voiced the ASL discussions into a tape
recorder. CART transcripts were also collected. The focus group facilitators reviewed audiotapes and transcripts of all nine focus groups, and identified common themes of discussion across the groups. After reviewing the materials, two researchers generated coding categories to facilitate analysis.

The study was approved by the Institutional Review Board of the University of Pittsburgh Medical Center. All participants were volunteers for the focus group and consented to participate. Participant names and characteristics are fictionalized in this report to preserve anonymity.

Results

Despite differences in culture and language across the nine groups, some general themes of discussion emerged. Nonetheless, notable differences between ideas for outreach, information access and needed services were evident between the groups. The succeeding sections describe these similarities and differences within major thematic categories.

Communication

Both Deaf and hard of hearing interviewees reported that language fluency with their provider was of paramount importance for learning about their illness. Consumers wanted to learn about all aspects of their illness so that they could make informed choices about their recovery. All interviewees also felt that their hearing loss or “Deafness” had a negative impact on their potential for recovery. Hearing peers were perceived by group participants to have access to community support programs, housing and supportive living arrangements, peer support groups and supportive employment opportunities to which the group participants did not. Furthermore, interviewees universally described that their communication needs dramatically affected their capability to use existing services effectively.

The process of giving and receiving information and other communication-related issues were discussed extensively in all groups. Often it was reported that the consumer could not find health care professionals who were Deaf or fluent in ASL, nor professionals who were aware of how hearing loss affected mental health. Furthermore, it was reported that interpreters were not available at provider visits, for a variety of reasons. These communication and information gaps led to strong feelings about limited access to the mental health system.
Feelings

Interviewees often reported a sense of frustration in their pursuit of mental health care and a delay in finding culturally appropriate services. The frustration for some turned to anger and for others a sense of resignation. One Deaf man named Edward had a stroke and was not provided an interpreter for medical or mental health appointments. He stated:

I wanted to know whether I would ever be able to use my arm again. My stroke made it impossible for me to communicate in sign language at all anymore. I wanted to kill myself and I didn’t want to write this sort of mindset related stuff back and forth on a note pad. I wanted answers, I wanted to know what was going to happen to me. I wanted to communicate in my language, so that I understood what was happening to me. I quit going for physical therapy too because I was so frustrated and angry by meeting with those people. My depression kept getting worse and worse, and I just wanted to kill myself.

Fear about misdiagnosis and institutionalization was particularly relevant for Deaf and DeafBlind individuals who communicated in ASL. One Deaf consumer named Robert, talked about his recent inpatient hospital experience. He said:

I was recently at a hospital where no Deaf people go. They treated me as if I was some kind of research object. They looked at me like I was some kind of research paper to write up because I was Deaf and I had schizophrenia too. I didn’t trust the motives of staff. They didn’t pay attention to my background or what I was struggling with. I was very afraid for my life and I was distrusting of them.

Isolation and loneliness were universally reported in the DeafBlind group. One culturally Deaf man who is blind said, “We are the loneliest people on earth...we don’t find out information for months even about world events much less about treatment options for depression. No one cares about us. It takes time to communicate with us and no one wants to take the time.”
Access to care was also affected by fears. One woman named Loretta from the focus group comprised of people who were DeafBlind stated:

My first focus is safety. I am isolated and lonely because I am afraid to go out....I rarely leave my house. I am afraid to go outside my house unless it is an absolute emergency. So I do not continue to leave my home for weekly therapy to go on a van with a total stranger in order to come to the clinic for counseling. It may take me three hours to get there with those transportation vans.

Language

There were prominent differences between the focus groups as to whether group members valued fluency in ASL, and what peer group they sought as they tried to access services. Deaf interviewees who communicated in ASL, family members of Deaf consumers, and DeafBlind individuals expressed an ideal preference for learning information and seeking assistance from providers or peers who knew ASL. A 25-year-old Deaf woman named Kathy stated:

I think that if someone knows your language and has a general respect for your cultural values or is Deaf themselves, there is less chance for them misdiagnosing or misunderstanding you. If a person communicates in my same language, I can ask questions easily, and I don't feel stupid. I want to learn about new things or things that I am worried about in a one-to-one setting with someone that I can understand...so I can have a dialogue. I want to be with people like me and I want to have professionals who work with me who communicate in my language or at the very least use an interpreter.

Conversely, group members who used English and amplification or CART did not seek to find providers who knew ASL. Neither did members of the focus group who had hearing loss, but who did not communicate in ASL, prefer being with others who used sign language. However, they did want providers and peers to be educated about the nuances of adjustment to hearing loss, understanding amplified speech, possible effective accommodations, and
assistive technology that would facilitate making a diagnosis and help to ameliorate symptoms.

**Health Information**

There were distinct differences reported between the groups as to where they turned to learn information about mental health and how they found area resources that were accessible to them. Deaf persons who knew ASL tended to learn and trust information that they gathered from others in their community who also knew ASL. Many consumers in the group where ASL was the primary language, were referred to mental health care by a friend, a rehabilitation counselor for the Deaf, or a Deaf friend who had been in counseling themselves. Family members of Deaf individuals stated that they often looked back to trusted professionals in other fields, such as educators whom they had encountered when their child was enrolled in school. Mrs. Glidden from the family group said, “My son is 32 years old, but I found help for him by calling his school….fourteen years after he graduated, but I figured someone there ought to know where to find a counseling place where they would help Deaf people.”

Hard of hearing people described that they turned to their primary care physician or audiologist for answers or information about counseling resources. One participant in the hard of hearing group who communicated primarily using spoken English, stated, “We use therapists that are in the same counseling system as hearing people typically, but then these therapists usually don’t know anything about how hearing loss affects mental health, and so we have to teach them.”

Participants also described less interpersonal methods of acquiring information. One hard of hearing person stated, “We use phone books, the internet and any information we can find with our eyes…brochures in the doctor’s office.” Similarly, participants from all focus groups regardless of language valued finding information on the internet if it was comprehensible to them.

Considerable differences were noted between the groups as well in their general knowledge base about the role of a therapist and the goals of mental health care. Deaf consumers who communicated in ASL were often not aware of the various types of therapies, the rationale for group therapies, and the roles of an addiction counselor.
Most interviewees reported a general problem with finding resources and counselors who provided services to persons who are Deaf, DeafBlind or hard of hearing. In all nine groups there was unanimous reporting that there is no unified place to find resources about mental health for persons who are either hard of hearing, Deaf or DeafBlind. One woman stated, “You know you can call Area Agency on Aging and this great lady there knows everything there is to know to help seniors....what about us? We need a directory to find services for Deaf, DeafBlind and hard of hearing folks and their families or a resource line for us.”

In all the groups, participants often did not self-advocate. The details of the Americans with Disabilities Act (ADA) were not well known. Deaf and DeafBlind consumers did not know how the law applied to them. Group members often did not know that the health care provider was responsible for paying for an interpreter during their office visit or hospital stay. No one in any culturally Deaf group knew where to find effective advocacy support if an interpreter was not hired for them. They did not know about various advocacy organizations in the state that could help them.

Group participants had many practical ideas about how to raise awareness about resources and ways to spread information about mental health-related topics. Focus group members universally reported that professional education (in-services) and talks to social clubs and area support groups would be helpful. Topics to include, they thought, would be about area resources, the Americans with Disabilities Act, advocacy-related information and mental health-related topics.

The groups differed, however, as to which specific audiences these in-service trainings should be prioritized. Hard of hearing group members suggested that presentations could be given to such organizations as Hearing Loss Association chapters, audiologist conferences, assistive device clinics and family practitioners’ grand rounds. For groups where ASL was the primary language, group members expressed a desire for trainings to be directed to their support system, such as area Deaf clubs; and furthermore, expressed a desire to personally learn more about their insurance, the ADA law, mental health and area resources and social service and advocacy organizations that could help them. Transition age consumers and parents of consumers suggested the idea of periodic seminars or a fair where they could learn more about area resources and services that were available. Finally, all nine groups suggested a website where information could be posted would be helpful to their communities.
Priorities for Mental Health Service Development

Deaf and DeafBlind consumer groups where members utilized ASL had a strong preference that, for any new services that are developed, staff who are employed should be Deaf or absolutely fluent in ASL. Consumer and therapist group members expressed a concern that despite laws such as the ADA, Deaf persons who need an interpreter are rarely admitted to extended day programs. These include partial hospital programs, behavioral health skills training program, psycho-educational training programs or drug and alcohol programs. They described a perception that this was because providers are reluctant to hire an interpreter due to cost concerns. This financial consideration was felt to limit treatment options dramatically. All groups concurred that there are no clear solutions emerging to solve this problem. Ultimately, the groups viewed dedicated monies to underwrite the cost of interpreters as necessary to avoid discrimination that they report commonly occurs when they are referred for long-term partial hospital programs, housing facilities or addiction-related counseling or rehabilitation services.

Regarding new services that should be further developed in the community, Deaf consumers and their family members cited as a top priority the need for personal assistance services.

Our loved ones historically miss information that is important to them. They may not be able to read or understand their mail and such things as insurance information. They may sign up for a scam or be taken advantage of easily. Mistakes are made because loved ones do not have enough information, can't read or can't easily talk to others to find out the 'real truth'.

Deaf consumers and their family members suggested the idea of a place to drop in to get personal assistance with bills, medical decisions and phone calls.

DeafBlind group members were adamant about the need for consideration of the development of a Support Service Provider (SSP program) in western Pennsylvania as a means to increase autonomy and encourage independent living capacity. Members described a system of specially trained support personnel who work with individuals with both hearing and vision losses, similar to what is available in some cities. Helen Keller National Center has created a service description for SSPs. "SSPs provide visual and environmental information, sighted guide services and information accessibility to empower
DeafBlind individuals so they can make informed decisions and would make it easier for persons who are DeafBlind to access behavioral health care too.”

All groups discussed the idea of developing peer support services to be provided by a person “like them”. For example, the idea of a culturally Deaf person in recovery could mentor a Deaf person; a hard of hearing person could mentor a fellow hard of hearing person and the same for a DeafBlind person as well.

Support and training for independent living skills were identified in all groups as a sorely needed service. Interviewees in each focus group also mentioned specifically the need for life skills training, advocacy training, maintaining personal safety in the community, budgeting, employment supports, mobility training, environmental awareness, and assistive devices.

All groups also raised the issue of developing more self- and family-help groups. For example, parents wanted groups designed for them to learn about resources and about how to best help their loved one with decisions that affected their lives.

The need for supportive housing was another priority that was clearly articulated. Deaf and DeafBlind group members had obviously reflected on this at great length.

It is very difficult for a Deaf person to find any housing. There is a great amount of discrimination even if you are a Deaf person who doesn’t have a mental health problem. It becomes even more difficult to find safe housing when we also have a mental health problem. We need supportive housing or modular homes or something like that, where we could all live in the same area if we chose to and still have independence. Then we could move out when we were ready.

Transition age individuals conceptualized a renovated apartment building with a “house parent.” “That way we could all be near to each other who knew our language if we got stressed out or if we needed information about something. We wouldn’t have to worry about getting raped or anything.” A DeafBlind woman said, “We need a place to live together, assisted living, personal care, independent or supportive living program or whatever...we don’t want to live and die alone. In New York City there are high rises specifically for DeafBlind people so they don’t have to live in fear and die alone.”
The idea of in-home therapy services arose frequently. DeafBlind consumers stated,

We know that it is important to meet with other people outside our homes, but it takes hours to get to therapy appointments on public transportation vans. Last week there was a bomb threat in the Parkway tunnels... so I sat in the cab for two hours and no one told me what was going on....These kind of problems make DeafBlind people prefer to not come out of their homes for therapy...so the idea of someone coming to see us is a good one.

Underemployment and unemployment were also a common issue that affected mental health and insurance status as well for all groups. Transition to work and supportive employment programs that were accessible to hearing people were not accessible to group members. One consumer reported, “I have a graphic arts degree and I was recently offered a job putting clothes on hangers. I want to do something in my field, but no one wants to take a chance on me because I am Deaf and mentally ill. We need supportive employment opportunities and an opportunity to learn employment skills. Many of us have never worked or have not worked for a long time.”

Discussion

Deaf, DeafBlind and hard of hearing interviewees reported on their experiences, feelings about current services, outreach strategies, and ideas for service development. The use of focus groups allowed us to gather unique insights into important ideas concerning ways to improve outreach and expand on existing mental health services that are culturally appropriate for different groups of persons with hearing loss. The use of focus groups allowed us to learn about participants’ perspectives and experiences. The organizing of the groups by language, accommodation preferences and co-occurring visual loss allowed us to explore differences between groups of people with hearing loss.

Some commonalities between the groups emerged. A common feeling of frustration when trying to access the mental health system was reported. Communication breakdowns during clinical encounters made consumers feel that many mental health professionals did not understand the unique needs
of persons with hearing loss or deafness. These general feelings led many to avoid mental health care unless it was an emergency.

Significant differences between groups were notable, even about specific terminology. Differences between the groups about terms commonly used in mental health became apparent. For example, the phrase “social worker” had very negative connotations among some group members who used ASL. For some group members this term “social worker” evoked fears of a children, youth and family agent they believed historically would perceive Deaf parents as incompetent and take their children away.

Differences in preferred methods of learning about mental health services also were quite different between the groups. These differences in preferred ways to learn new information seemed to be related to language.

Interviewees who identified ASL as their language tended to learn about community resources by “word of mouth” at community gatherings, cultural events or on listserves to which they were subscribed. Some learned information on the internet. Deaf and DeafBlind interviewees expressed a desire for outreach talks at their community centers, social gatherings and support groups as a way to learn new information.

Hard of hearing group members typically learned about mental health resources by searching in a phone book or looking on a website. Hard of hearing group members thought that it would be helpful for audiologists and primary care physicians, and in advocacy groups such as Hearing Loss Association chapters to receive information about behavioral health related services in the region.

All groups valued the idea of a resource center or a place to call for help, or a drop-in center or call center for persons “like them.” A website where area resources could be posted was also suggested.

Language and culture played a significant role in ideas about service development. Interviewees who used ASL or were DeafBlind had well-formulated ideas about the need for case management, as well as drop-in services, peer support, and housing where they could be with others who shared their language or their dual sensory condition.
Lastly, interviewees offered sensible solutions for improving mental health informational campaigns to their respective groups. All were thankful about the opportunity to provide input into community service development.

Due to the feedback from these focus groups, several community interventions and actions have recently been undertaken. First, a grant from a local community organization led to the development of a mobile mental health team. This team includes a Deaf staff member and a therapist who can provide community outreach talks to raise awareness about mental health, social services, advocacy-related information and area resources. Other members of this new team now provide counseling and living skills assistance to consumers in their home.

Second, a new website at www.healthbridges.info was created to provide advocacy-related information and mental health education, in both English and ASL. Third, a committee was convened to generate a self-advocacy or “Accommodation Card” to raise awareness about patient communication rights. This card can be individualized and downloaded from the newly created website.

Finally, community leaders, mental health providers, consumers, and program planners recently applied for a grant for an eight-bed independent housing facility in which consumers could reside.

This study gathered ideas to aid in outreach campaigns and service development for persons with hearing loss who reside in Western Pennsylvania. The study does have limitations. The views of the participants may not represent the state or the U.S. Deaf, DeafBlind or hard of hearing populations at large. Nearly three-fourths of the participants in our study were involved in mental health treatment or in a support group. This makes our sample atypical, because few people with hearing loss successfully engage in therapy.

We did not seek the opinions of consumers from a diverse geographic region, or who lived in exclusively rural areas. We focused only on the recruitment of adult consumers who resided in Western Pennsylvania who were geographically near to services in a select metropolitan area. We did not specifically recruit persons in this study who had co-occurring intellectual disabilities, senior citizens or children.
Conclusion

These focus groups represented a unique way to gather information to examine differences and similarities between groups of people with hearing loss about service development and ways to raise awareness about mental health. Further research in larger, more representative populations of Deaf, DeafBlind and hard of hearing groups is needed to provide information amenable to quantitative analysis and to assure generalizable results. Consumers in this study did report that significant differences existed in preferred ways to acquire information about mental health related topics. In addition, significant differences emerged in what services were valued by consumers in the different groups. Thus, a “one size fits all” model will not work to meet the diversity of needs that face persons with hearing loss who seek mental health services.

There appear to be many unique needs and preferences related to housing, group therapies and acquisition of independent living skills for persons with hearing loss or multi-sensory disability that may be unique to them. It is evident that language, culture and accommodation needs are important variables to consider in planning for the development of a true continuum of recovery-oriented services to benefit consumers with hearing loss or deafness.

In summary, information gleaned from consumers in these focus groups informed recent advances in programming throughout Western Pennsylvania. The focus group process fostered a spirit of collaboration and community problem solving between community members and helped to set a stage for future work together.

Acknowledgements

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Table I. Focus Group Participants

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<th>Group</th>
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<th>Language</th>
<th>Ages</th>
<th>Race</th>
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<td>8 C</td>
<td>2 M 6 F</td>
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<td>3 F</td>
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<td>35-74</td>
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<td>3 C</td>
<td>3 F</td>
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<td>40-55</td>
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<td>6 M</td>
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<td>18-21</td>
<td>2 AA 4 C</td>
<td>3 M 3 F</td>
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Legend:
AA: African American; C: Caucasian; F: Female; M: Male
Appendix

Informational Probes for the Focus Groups

• How do you first learn about health topics and where to turn for help?
• Where do you learn new information about health care topics? (cholesterol, depression, etc.)
• How do people who are Deaf/DeafBlind or hard of hearing find out about where to go for help with such things as depression and drug or alcohol use?
• What aspects of behavioral health care work well in our region and what aspects need improvement?
• What type of information is needed by your community (or among people who have hearing/vision loss like yourselves)?
• What would make it easier for people to go for services like counseling or treatment for emotional or drug problems?
• What kind of mental health supports or programs would help Deaf people/hard of hearing/DeafBlind people have an opportunity for improved mental health outcomes, once they get depression, schizophrenia or bipolar illness for example?
• If there was a resource or support person who could go into the community to help people get connected to services, what kind of help should that person be able to provide?
References


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Address:__________________________________________________________________________

City:________________________ State:____ Zip:_______ Phone:__________________________

E-mail:______________________________________________________________________________

Please list any certifications (e.g., CRCC) or special training: ____________________________

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☐ Hearing
☐ Late Deafened
☐ DeafBlind

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