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Elizabeth Eckhardt
none

Annie Steinberg

Douglas S. Lipton

Louise Montoya

Marjorie F. Goldstein

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Elizabeth Eckhardt, M.S.W, Annie Steinberg, M.D., Douglas S. Lipton, Louise Montoya, M.A., Marjorie F. Goldstein, Ph.D.

Abstract

This article will report the steps and procedures implemented in the development and testing of the Diagnostic Interview Schedule for the Deaf-IV (DDIS-IV). The DDIS-IV is a standardized mental health assessment instrument developed for use with individuals who are deaf, it is self-administered in American Sign Language (ASL) on laptop computer. This research is supported by a Small Business Innovations Research Grant from the National Institute of Mental Health. The translation procedure consisted of two translation teams, advisors, and back translation. The technological procedure included the digital videotaping of assessment items in ASL, the use of interactive video software and the development of a database and scoring program. During the testing phase, individuals who are deaf and receiving inpatient and outpatient mental health services will be tested two times, once using the self-administered version of the instrument and the second time receiving the same test in ASL by a mental health clinician.

In 1996 Social Science Innovations Corporation (SSIC) at National Development and Research Institutes, Inc (NDRI) was funded by the National Institutes of Mental Health for Phase One of a Small Business Innovations Research grant (SBIR). Phase One of this research investigated the feasibility of translating the Quick Diagnostic Interview Schedule-III, Revised (QDIS-IIIR) into American Sign Language (ASL), signed English and speechreading. During Phase Two, we will develop a self-administered laptop computer version of the QDIS-IV, a computerized version of the Diagnostic Interview Schedule-IV (DIS-IV) in ASL. We will utilize Interactive Video Technology (IVQ), an effective method of surveying the deaf population used to interview more than 850 deaf individuals regarding their substance use (Lipton, Goldstein, Fahnbulleh & Gertz 1996: Lipton & Goldstein 1997). The DIS-IV is a standardized psychiatric assessment interview, which covers a large number of the diagnostic categories from the Diagnostic and Statistical Manual-IV (DSM-IV), the official mental health diagnostic system in the United States.

The Diagnostic Interview Schedule was selected for several reasons. Foremost among its' advantages are: it can be used as a clinical diagnostic instrument and epidemiological instrument; its' adaptation for

varied cultural linguistic groups, has been translated into 12 languages; it is precoded; and it has been tested with both the general population and patients receiving mental health services (Robins, Cottler, Bucholz, & Compton, 1998). This paper will describe the complex process of translation and the manner in which we are addressing the cultural and linguistic challenges inherent in the translation of an English language based instrument into American Sign Language.

Phase One

Phase One of this project explored the feasibility of translating selected QDIS-IIIR diagnostic sections into American Sign Language, Signed English and Speechreading. Selection of sections was determined by following the prevalence of diagnostic disorders in the general population as determined by the Epidemiological Catchment Area Study, a multisite collaborative study of mental disorders in the general population (Helzer, Robins, McEvoy, Spitznagel, Stoltzman, Farmer & Brockington, 1985). These sections included Generalized Anxiety Disorder, Simple Phobia, Agoraphobia, Social Phobia, Manic Episode/Bipolar, and major Depression. The process of testing the feasibility of translating the QDIS-IIIR into American Sign Language, Signed English, and Speechreading incorporated two major stages, translation/back translation of QDIS-IIIR diagnostic sections and focus groups to obtain feedback from the deaf community.

Translation Stage.

Strategies for translation between spoken languages and for written material used in research which are recommended by Edwards (1994) and Philips, Hernandez and Ardon (1994) respectively, were utilized. The goal of translation for research is to achieve "equivalence" between different language versions of an instrument in order to facilitate comparison between groups while retaining the psychometric properties of the original instrument (Edwards 1994). Translation equivalence incorporates more than the task of linguistic equivalence. Translation equivalence must comprise: conceptual and functional equivalence which occurs when a construct can be meaningfully discussed in both cultures (Hui & Triandis, 1985); operational equivalence which is evident when clearly identifiable features of a phenomenon are equally meaningful in both cultures being studied; item equivalence which occurs when an item in both languages has the same meaning to both linguistic and cultural groups and can be directly compared (Van de Vijer & Portinga, 1982); and scalar equivalence, which is achieved when a value on a scale identifies the same level of intensity of

a construct for both groups, this is often the most difficult to attain (Van de Vijer & Portinga, 1982; Hui & Triandis, 1985).

Edwards (1994) and Phillips et al. (1994) cite three strategies for attaining translation equivalence: decentering, back translation, and a committee approach to review of the translations. These strategies are being employed in the translation of the QDIS-IV into American Sign Language. Decentering encompasses the process of translating to the target language, back translating to the source language, and negotiating the modification of both the source and target language as needed. These steps insure that the original construct is as conceptually, linguistically, culturally and operationally as equivalent in both languages as possible.

Back translation is the second step in the translation process, after the items have been translated, in this case from written English into American Sign Language. Back translation is the process of blindly translating the American Sign Language translation of the document back into its original language, English, with the goal of obtaining translations that maximize the equivalence of meaning. The back translator(s) are bilingual and unfamiliar with the original instrument being translated. The committee approach is used to negotiate the modifications to both versions in order to most effectively retain the integrity of the original language.

Translations were completed by a team consisting of two prelingually deaf individuals and a mental health clinician/researcher experienced working in mental health settings with individuals who are deaf. Each item from the selected QDIS-IIIR sections was reviewed by translation team members to ensure clarity of intent and content, and potential translations were explored. A deaf member of the translation team was videotaped signing one or more versions of each item. The videotapes were sent to an advisory panel of experts in the field of mental health and deafness, including mental health clinicians who are deaf themselves and a psychiatrist who is both fluent in American Sign Language and experienced in working with individuals who are deaf. The advisory panel assessed the clarity of and equivalence with original items, selected the most effective translation version of each item, and offered suggestions for additional translations when necessary. One version of each translated item was selected and this videotape was then forwarded for back translation.

Following established practices (Karno, Burnam, Escobar, Hough & Eaton, 1983) and incorporating methods adapted for the American Sign Language translation of the Minnesota Multiphasic Personality Inventory (Brauer, 1993), back translation achieved translation equivalence between English, American Sign Language, and signed English versions. A bilingual (American Sign Language/English) individual, blind to the original text,

translated the American Sign Language and signed English items back into English. These English back translations were then compared to the original QDISIII-R items and reconciled. Dr. Robins, senior DIS/QDIS author, was consulted to confirm equivalence to original items.

Focus Group Stage

Six focus groups, each limited to six to eight individuals from diverse sectors of the deaf community were recruited and grouped by communication preference and education. Focus group facilitators were fluent in American Sign Language and experienced in leading deaf groups. In total, six focus groups were facilitated to review the respective translations (four for American Sign Language translations, one for the signed English translations and one group for speechreading).

Focus groups (N=39) were comprised of 16 males and 23 females, 53 percent of whom were between ages 26 – 40 (21percent between 18 – 25 ; 26 percent between 40 – 75). Forty-nine percent were Caucasian, 33 percent African American, and 18 percent Hispanic. Deaf adults with some post-secondary education are over represented in the sample (41 percent versus 9 percent nationally), somewhat limiting the generalization of the findings. Two thirds of the participants reported American Sign Language as their primary method of communication, 21 percent identified Signed English and 12 percent identified Speechreading (Steinberg, Lipton, Eckhardt, Goldstein & Sullivan, 1998).

Focus groups were limited to two hours in duration. Facilitators welcomed the participants and described the study and procedures, written consent forms were explained in the preferred language modality and completed by those willing to be videotaped. Participants were informed that they were not required to answer the questions they would be reviewing but instead to comment on the clarity, expression, affect, speed, and their sensitivity and comfort with subject matter. Focus groups were videotaped for transcription purposes and to view suggested phrases in American Sign Language or signed English. Translation effectiveness and equivalence were examined by comparing individual item meanings as understood by focus group participants with the intended meaning for hearing subjects. Feedback regarding speed, affect and clarity were also reviewed and suggestions noted.

Findings from the translation and focus group stage are categorized into two parts, Translation Issues identified by the translation team and Focus Group findings.

Use of Interactive Video Technology in Assessment

Translation Issues

The translation team noted several issues as problematic during the translation process. Concepts of time and duration as phrased in the QDIS-IIIR were often difficult to translate, for example, phrases like "at least one month" and "for six months or more". Furthermore, concepts of time-within-time were even more difficult to convey in American Sign Language, e.g., "Have you experienced [insert symptom] for one month or more during the past year?"

The idiomatic nature of several QDIS-IIIR items also presented the translation team with the challenge of maintaining the original meaning of the question, while accurately translating expressions such as "feeling on edge" or "keyed up". In addition the paucity of signs for the fine distinctions in mood, and some symptoms and constructs that do not equate cross-culturally proved challenging (Steinberg et al, 1998).

Focus Group Findings

Focus groups conducted in American Sign Language confirmed the translation teams findings of difficulties in translating time-within-time and duration, English idioms, and subtle distinctions in emotional states. The Signed English focus groups reported that the signing was "very clear", these participants also reported relying more heavily on the captioning than the other groups. The speechreading focus group found the clarity of the model "exceptional" (Steinberg et al, 1998).

Focus group participants applauded the availability of three modalities (American Sign Language, signed English, and speechreading), some stated that this demonstrated sensitivity to the diversity of the deaf community. Many participants reported discomfort discussing mental health issues, but agreed that having the questions asked in their own language, "without a third party" is helpful.

Focus group participants made several suggestions to improve the quality of the potential product, for example, it was suggested that a replay button be added to relieve pressure to capture the meaning of each question on first viewing. Focus group participants also suggested that the caption "match the model's speed of communication".

Focus group participants emphasized the need for the sign model to remain neutral in her expression when conveying certain symptoms in order to refrain from leading respondents in any way. Some focus group participants mentioned and the majority agreed, that some health providers may try to satisfy the Americans with Disabilities Act requirements for "effective communication" using this instrument in lieu of qualified interpreters or sign language competent health professionals. They

recommended that health professionals administering the instrument be competent in sign language and trained in working with individuals who are deaf (Steinberg et al, 1998).

In summary, most QDISIII-R items were translated effectively, however idioms and time related issues required further attention. Phase One of this study successfully demonstrated that a computerized version of a signed mental health diagnostic interview can be effectively translated and accurately utilized with most deaf individuals.

Phase Two

Currently we are completing year one, Phase Two of the Small Business Innovations Research grant's two year funding cycle. Phase Two will incorporate the translation of selected QDIS-IV sections, prototype development and testing, and pilot testing. Ultimately, two products will be developed: (1) The Diagnostic Interview Schedule-IV for use with individuals who are deaf (DDIS-IV), a revised version of the DIS-IV (a standardized psychiatric assessment instrument) and; (2) The Quick Diagnostic Interview for use with individuals who are deaf (Q-DDIS-IV), a revised version of the QDIS-IV (a self administered computerized screening version of the DIS-IV). The Q-DDIS-IV will essentially differ from the DDIS-IV in that it will act as a diagnostic screener and will require less time to complete. Health professionals, skilled in the field of mental health and deafness will be given the option of administering the Q-DDIS-IV or the DDIS-IV. The DDIS-IV, is likely to be an effective research instrument because it will not skip respondents out of a section when they meet the minimum number of positive or negative diagnostic criteria; thus enabling the computer to generate a full list of symptoms.

Both instruments will include seven sections from the DIS-IV: Phobia (which includes Specific, Social and Agoraphobia and Panic), Alcohol Abuse/Dependence, Generalized Anxiety Disorder, Depression/Dysthymia, Antisocial Personality Disorder, Obsessive Compulsive Disorder, and Schizophrenia. Selection of these sections was determined by the prevalence of diagnostic disorders in the general population (Robins et al. 1998). Although the prevalence of these diagnoses may be different in the deaf population, there is no available data on this subject in the psychiatric or deaf-related literature. In the absence of epidemiological data citing the prevalence of psychiatric disorders among the deaf, we presume that these conditions exist in high frequency in the deaf community as well. The DDIS-IV/Q-DDIS-IV will generate lifetime and current diagnoses but will not include questions pertaining to remission, recurrence and onset.

Method of Translation

The translation procedure employed during Phase One was altered for Phase Two. The Phase Two translation procedure includes two translation teams working simultaneously to complete the translations in a timely fashion. Translation teams are comprised of three individuals: one who is deaf, of deaf parentage, whose native language is American Sign Language and who is a National Registry of Interpreters for the Deaf (RID), Certified Deaf Interpreter, specialty certificate: legal interpreting; a bilingual child of deaf adults whose native language is American Sign Language, who holds a degree in mental health counseling, is RID certified with a Comprehensive Skills Certificate and holds Level V certification from the Texas Commission for Deaf and Hard-of-hearing; and a bilingual mental health counselor/American Sign Language interpreter. All team members have experience working with individuals who are deaf in various professional settings including court and mental health settings. Diagnostic disorder sections were divided among translation teams. Translation tasks such as sign modeling for the translation process, documenting video log and programming notes, and editing videotapes were divided among translation team members

Initially, the translation team members review the written English item and confirm understanding of the content, intent and conceptual meaning of the question or item in English. The team then explores various ways of translating each item into American Sign Language. One member of the translation team is then videotaped signing one or more versions of each item in American Sign Language. The team is careful to capture the most effective expression of each item to avoid "leading" the respondents.

Because the DIS-IV is comprised of items that incorporate complex time frames and concepts, the translation team often finds it necessary to divide items into one or more parts. When the original item is altered, Dr. Lee Robins, author of the DIS-IV is contacted to ensure that the alterations maintain the intent and content of the original item. The programming notes document filenames and intricate alterations and revisions to original items. Translation team members work closely with staff at the media company to ensure that programming is correct.

Occuring simultaneously to the process of determining translations, completed videotaped American Sign Language translations are reviewed by an advisory panel comprised of a bilingual psychiatrist experienced providing psychiatric assessment services to individuals who are deaf and a Masters level mental health clinician and researcher experienced working with deaf patients. The advisory panel discusses complex diagnostic sections with the translation teams before the translation process begins,

and provide feedback regarding the most effective means of maintaining the original intent and content of the questions being translated. In addition, an ASL advisor, a Deaf research professional who has extensive experience translating written English into ASL, reviews the videotaped translations and provides critical feedback. Advisory panel members and the ASL advisor often make suggestions regarding expression of the signer, offer potential revisions to translations and determine which version is most accurate. The multi-media computer programmer, not originally conceptualized as an integral part of the translation process has become an invaluable resource in conceptualizing translations which lend themselves to a cd-rom version of a mental health instrument. Videotapes are also sent to the back translator who translates the ASL versions back into English. Upon collecting feedback from the reviewers and the back translator, the translation team reviews the back translation and feedback and makes any necessary revisions and reshoots. These revised videotapes are reviewed once again by members of the advisory panel. A final edited version of the videotape is sent to the sign model, who is given time to review the translations before the final video shoot date. The sign model is a deaf individual whose primary modality of communication is ASL, with previous sign model experience specific to mental health material.

Prototype Development

As a first step, the above translation procedure was utilized to develop a prototype of the Depression section of the QDIS-IV. The prototype was developed to determine the amount of time necessary for the translation process, as well as the amount of time needed to develop a scoring program, videotape, digitize, and program one section of the DIS-IV. The Depression section was selected because of the prevalence of this diagnosis among both deaf and hearing populations, and because it is one of the more complex sections to program. The prototype also provided the opportunity to pilot an important section of the instrument in the deaf community.

Eleven individuals who are deaf participated in a focus group during which they interacted with the prototype to provide feedback regarding ease of use of the laptop, length of time needed to become comfortable interacting with the instrument, average length of time to answer each question, screen layout (buttons, colors, text), signing expression and signing speed. These deaf individuals were recruited from a residential program run by a community mental health clinic for individuals who are deaf. The focus group was facilitated by two professionals experienced in working with individuals who are deaf and

knowledgeable of focus group dynamics. Each participant interacted with the prototype for 15 minutes, and was then shown two versions of a specific item. These items, named "Topic Boxes" are assigned to appear frequently throughout the interview. Topic Boxes were developed to solve the problem raised in Phase One regarding difficulty in understanding complex time frames used in the DIS. These Topic Boxes eliminate the need to frequently repeat complex time frames in American Sign Language. The signer is shown in a small box in the corner of the laptop which can be clicked "on" at any time to display the signer informing the subject about the relevant time frame.

The following are problems and comments reported by focus group participants and our responses to each; (1) difficulty working with the laptop's built in mouse. A mouse will be attached to the laptop for future testing. 'Hot Keys' were also developed on the keyboard for ease of use, i.e. subjects could hit Y for Yes, N for No and X for Next; (2) feedback indicated that the text was too small. Text will be enlarged to address these concerns; (3) responses to the Topic Boxes were mixed. Thus, the tutorial will clearly explain the intent of the Topic Box and how to use it; (4) feedback pertaining to speed and expression of the sign model were favorable.

Testing

The method of testing the efficacy of this instrument requires the testing of individuals who are deaf and receive mental health services in various settings including inpatient, outpatient and residential. The DDIS-IV/Q-DDIS-IV will be deployed at cooperating sites. There, research staff and consultants will initiate testing of its efficacy as a screening instrument including consumer acceptance, files serviceability, portability and necessity for maintenance. Each subject will be tested two times: psychiatric diagnosis derived from the computer-administered Q-DDIS-IV and a human clinician administering the Q-DDIS-IV in American Sign Language. This clinician will be fluent in American Sign Language and will have experience assessing, diagnosing and treating individuals who are deaf in mental health settings. Unlike the computer-administered version of the Q-DDIS-IV, the human clinician will have the opportunity to use various methods of ensuring that the subject comprehends the items in American Sign Language (i.e. using various translations of each item and assessing through body language, gesture whether the subject comprehends the material). The interval between the first and second test administration will be no less than one week and no more than three weeks. The one week minimum between test administration should minimize practice effect,

9

while the three week maximum should assure that the recent symptoms are within the time criterion of the QDIS-IV.

At each of the participating sites, a pool of subjects will be selected for the validation of the Q-DDIS-IV. Subjects will be 18 years of age and older, of various ethnic, racial and socioeconomic backgrounds, whose primary mode of communication is American Sign Language and who are currently receiving mental health services. In order to select individuals with a wide range of mental health disorders, at each facility charts will be reviewed for chart diagnosis. While we recognize these diagnoses are often given without any standardized diagnostic procedure for assessing individuals who are deaf, they will offer some indication of major diagnostic category. A list of patients will be compiled in each diagnostic category by the staff of the facility and staff will then randomly select individuals from these diagnostic lists. The clinician(s) will not be told chart diagnosis before administering the Q-DDIS-IV.

Patients will be contacted by the facility director or his/her designee and invited to participate in the project. Each individual will be offered an incentive payment of $50 for full participation ($20 for the first session and $30 for the second session). An Informed Consent Form will be shown to them in English and translated into American Sign Language. The right to refuse without recrimination will be carefully explained and it will be verified that this right is understood. The purpose of the research and process of the research protocol will be explained in American Sign Language.

The translation procedure being utilized for this study has yielded significant insights into the intricacies inherent in translating an existing standardized mental health assessment interview for use with individuals who are deaf. Documentation of translation issues specific to diagnostic categories will be forthcoming. Further endeavors are necessary to further research the effectiveness of these methods.

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Use of Interactive Video Technology in Assessment

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Ms. Elizabeth Eckhardt, M.S.W.
Marjorie F. Goldstein, Ph.D.
Douglas S. Lipton
Social Sciences Innovations Corporation
National Development Research Institutes
71 West 23rd Street
New York, NY

Annie Steinberg, M.D.
Louise Montoya, M.A.
Children's Hospital of Philadelphia
34th Street and Civic Center Boulevard
Philadelphia, PA 19104-4399