

YQOL-DHH

**Youth Quality of Life
Instruments –
Deaf and Hard of Hearing
Youth Module**

User Manual and Interpretation Guide

**1st Edition
2010**

Seattle Quality of Life Group



YQOL-DHH Youth Quality of Life Instruments - Deaf and Hard-of-hearing Youth Module

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**1st Edition
2010**

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YQOL-DHH



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ACKNOWLEDGEMENTS

This research was supported by a grant to the University of Washington from the National Institute on Deafness and Other Communication Disorders (#R01 DC008144-01A1).

We wish to express our appreciation to the following individuals for their participation in this work: Melissa Garafalo, Nancy Hanauer, Rob Roth, and Aimee Verrall. For helping recruit participants we thank the Washington, Arizona, and Phoenix Day Schools for the Deaf, Hands & Voices, Listen & Talk, Educational Audiology Association (EAA) and American Speech-Language Association (ASHA), as well as a number of public school systems and DHH youth camps around the country. We wish to acknowledge the special contributions of our co-investigator John Niparko and our key informants and expert advisors who freely shared their views on children and youth who are deaf or hard-of-hearing, and commented on YQOL-DHH and DHH-PROBE items.

Without the ongoing support of the University of Washington's Interpreter Services Program and its energetic and dedicated leader, Tobias Cullins, we could not have worked as closely and efficiently with our co-investigator and colleagues who are deaf or hard-of-hearing.





Suggested citation:

Patrick, DL, Kushalnagar, P, Skalicky, A, Schick, B, Topolski, TD, Edwards, TC, O'Neill-Kemp A. (2010). User's manual and interpretation guide for the Youth Quality of Life Instruments – Deaf and Hard-of-Hearing Youth Module (YQOL-DHH). Seattle, WA: University of Washington, Dept. of Health Services.



LIST OF ABBREVIATIONS

Abbreviation	Full text
ASL	American Sign Language
DHH	Deaf and Hard-of-Hearing
PSE	Pidgin Signed English
SeaQoL	Seattle Quality of Life Group
QoL	Quality of Life
YQOL	Youth Quality of Life Instrument
YQOL-R	Youth Quality of Life Instrument-Research Version
YQOL-SF	Youth Quality of Life Instrument-Short Form



INTRODUCTION

The Seattle Quality of Life Group (SeaQoL) at the University of Washington has worked for over the past 15 years assessing the quality of life among youth who are often Perceived Stigmatized by society.

Since its creation, the SeaQoL Group's objective has been to develop and distribute instruments that may be used to assess quality of life among youth with disabilities, chronic conditions, or who may for other reasons be marginalized by society.

This manual was designed to provide practical information on the *Youth Quality of Life Instrument – Deaf and Hard-of-Hearing Youth Module* (YQOL-DHH) as well as its administration, scoring procedures, psychometric properties, interpretation of results, conditions of use, and language translation.

Its purpose is to describe:

- The *YQOL-DHH Youth Module*
- How it is administered
- How to calculate the scale scores
- The meaning of the scores and their reference values
- The main measurement properties
- The available translations and linguistic validation methodology
- The conditions of use

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I. INSTRUMENT OVERVIEW

1.1. History and development

The YQOL-DHH Youth Module was developed by the SeaQoL Group with funding from the National Institute on Deafness and Other Communication Disorders. The instrument development was conducted in two phases: Phase I item generation and selection (2007-2009); and Phase II psychometric validation (2009-2010). The instrument was developed to assist clinicians and parents better understand the quality of life of youth with varying levels of hearing loss and to be used in determining the need for appropriate interventions. The instrument was originally developed in US English and was culturally adapted to American Sign Language. Version 1.0 of the YQOL-DHH was modified after phase II data collection and Version 2.0 is included with this manual.

1.2. Instrument description

The YQOL-DHH Youth Module is designed to assess the quality of life of youth with both acquired and congenital hearing losses and to complement the generic Youth Quality of Life Instruments – either the Research Version (YQOL-R) or the Short Form (YQOL-SF).

The **YQOL-DHH consists of $n=32$** perceptual items which factor into three domains, two which are positive, Participation and Self- Acceptance/Advocacy, and one which is negative, Perceived Stigma, but does not have an overall score.

Also available for use with the **YQOL-DHH are $n=28$** contextual (potentially observable) items fielded, but not assessed for their measurement properties.

The **generic YQOL-R consists of $n=41$** perceptual items tapping three domains of generic QoL: 1) Self: $n=14$ items, 2) Social: $n=14$ items, 3) Environment: $n=10$ items, and 4) General QoL: $n=3$ items. The YQOL-R produces an overall quality of life score, as well as four subdomain scores.

The **generic YQOL-SF consists of $n=10$** perceptual items tapping three domains of generic QoL: 1) Self: $n=3$ items, 2) Social: $n=4$ items, 3) Environment: $n=2$ items, and 4) General QoL: $n=1$ item. The YQOL-SF produces an overall quality of life score.

1.3. Instrument summary grid

Author(s)	<i>Donald L. Patrick, Poorna Kushalnagar, Anne Skalicky, Brenda Schick, Tari D. Topolski, Todd C. Edwards</i>
Stated Purpose of development	<i>Assessment of Quality of Life Among Children and Youth who are Deaf or Hard-of-Hearing</i>
Type of instrument	<i>Quality of Life Measure-DHH Youth Module</i>
Therapeutic area/Disease	<i>Congenital and Acquired Hearing Loss</i>
Population/Age	<i>Youth ages 11- 18 years</i>
Domains of Perceptual Items	<i>Participation, Self-Acceptance/Advocacy, and Perceived Stigma</i>
Total number of items	<i>32 perceptual items, 28 contextual items</i>
Response scales	<i>Perceptual Items: 11 point rating scale (with anchors outside the ends); Contextual Items: 5-point Likert scale</i>
Mode of administration	<i>Self-administered, Interviewer-Supervised</i>
Time for completion	<i>Median time: 15 minutes for paper administration; 30 minutes for DVD administration.</i>
Time recall	<i>Perceptual Items: Generally, at the moment; Contextual Items: Recall period either 7 days or 4 weeks</i>
Scoring	<i>General scoring rules: /score per domain/score per item/range of scores/direction of scores</i>
Existence of Normative data	<i>None available at this time</i>
Language	<i>Original language: English Available DVD translation: American Sign Language</i>
Conditions of use	<i>Information on Copyright license agreement/fees</i>
Related website(s)	<i>http://www.seaqolgroup.org</i>



1.4. Background: Why A Deaf and Hard-of-Hearing Module?

Previous studies of QoL among youth who are deaf or hard-of-hearing (DHH) have focused more narrowly on individual aspects of QoL, such as functional status and psychological well-being (Huber, 2005; Wake, Hughes, Collins, & Poulakis, 2004; Hawthorne et al., 2004; Karinen, Sorri, Valimaa, Huttunen, Loppoen 2001), peer relationship, self-esteem (Jambor & Elliott, 2005) and inclusive education (Leigh, 1999). These studies compared youth with hearing loss to children with normal hearing. Although generic measures are useful, instruments used with hearing youth may not accurately reflect the perspective of youth with hearing loss themselves. Using measures of outcome that reflect the “voices” of persons with hearing loss is important to the development and evaluation of interventions that are culturally and socially sensitive and inclusive.

We define “quality of life” as an individual’s “perception of a their position in life in the context of the culture and value systems in which they live, in relation to their goals, expectations, standards, and concerns (WHOQOL Group, 1994). This definition of QoL is broader and more global than either the concept of “subjective well-being” in reflecting the cultural and social context that defines the good life (Kahneman, Diener, & Schwartz, 1999) or health-related QoL (HRQoL), which focuses on functional limitations. This definition requires that youth and parents or guardians define the concepts and items, that the measure use subjective self-report whenever possible, and that the items be developmentally appropriate. It focuses on a positive emphasis on health enhancing aspects of life rather than a negative orientation found in most mental health assessments.

The YQOL-DHH module was constructed to augment the generic Youth Quality of Life Instrument (YQOL) developed by Patrick and colleagues (Edwards, Huebner, Connell, & Patrick, 2002; Patrick, Edwards & Topolski, 2002) for assessing perceptions among DHH youth ages 11-18 years (see YQOL-R Manual). A module specific to reported observations by parents of DHH children ages 5 to 10 years (DHH-PROBE) was developed and is available as well.





1.5. Development of the YQOL-DHH Youth Module

In developing the YQOL-DHH, 49 semi-structured, in-depth interviews with youth ages 11-18 years with a range of congenital and acquired hearing losses on how being deaf or hard-of-hearing affect their lives. In addition, an advisory meeting was held with clinical and academic experts (n=11) working in the field, in which the newly developed items were evaluated. The interviews with the adolescents formed the primary basis for item generation. The expert panel was used primarily as confirmation checks that no major issues were missing and for the purpose of reducing the large item bank generated by the adolescent interviews to a manageable amount.

The youth who were interviewed were purposively selected to represent a broad range of hearing loss: (1) mild (n=5); (2) moderate (n=8); (3) moderate-severe (n=6); (4) severe (n=7); (5) profound/CI (n=23). The main objective of this sampling approach was to articulate a diverse set of perspectives regarding QoL among children and youth who are deaf or hard-of-hearing and present with diverse communication preference and educational backgrounds.

The youth (ages 11 to 18) were approached to participate in the research project as "expert informants" to help design a questionnaire to assess adolescents' thoughts and feelings about their QoL. Individual interviews were conducted by one of five members of the research team experienced in qualitative interviewing. Interviewers fluent in sign language conducted interviews with youth signers. Interviewees were recruited until what they were telling us became redundant with what previous interviewees had said and little new information was gained.

Youth interviewees were invited to generally discuss their lives in relation to others their age, including values, goals, and expectations. Specific probes were used to illuminate stage-salient contexts of youth including home, school, work, and community (Bronfenbrenner, 1979), and how they perceived their lives were affected by having a hearing loss in today society. The other interview participants were asked similar questions regarding their view of youth QoL in general, and how they perceived it was affected by being deaf or hard-of-hearing.

In accordance with the WHO QoL definition cited above, we used the needs-based model to create the YQOL-DHH. The needs based approach to development of QoL measures builds upon functional status measurement and views QoL as the net result of a person's evaluation of how much their needs have been met including their evaluation of functional status and interaction with the environment. It is based on Maslow's needs hierarchy and was the basis for the WHO-sponsored measure of QoL (Skevington, 2002). Papers by Hunt, McKenna, and other instrument developers provide a further reference to this needs-based approach (Hunt & McKenna, 1992; McKenna et al., 2001). Thus, the items comprising the YQOL-DHH were selected to represent the areas of greatest salience as identified primarily by the youth who are deaf or hard-of-hearing themselves.





We generated an item pool from qualitative interviews with youth with a wide range of hearing loss, and input from clinicians working with deaf and hard-of-hearing youth. Normally we would have consulted existing measures for this purpose as well, but as discussed above, the instruments available in the field are focused primarily on functional limitations of hearing loss, anatomical variables, and psychosocial maladjustment. We found no existing instruments that reflected a needs-level approach to the assessment of QoL.

1.6. Qualitative data analysis and item development

A "grounded theory" approach guided data analysis of the interviews and focus groups (Glaser & Strauss, 1967). Grounded theory is derived from the sociological theory of symbolic interactionism (Blumer, 1969), and is used to model phenomena about which little is known, in this case, the QoL of youth who are deaf or hard-of-hearing. It is an inductive process approach, with an emphasis on social dynamics.

The investigators, previously experienced in this approach (Edwards, Huebner, Connell, & Patrick, 2002), worked with the transcribed interviews to code relevant QoL issues and to write items based as closely as possible on the views and language of the adolescents themselves. Data coding strategies included open coding, assignment of codes to the text based on words or phrases that captured meaning in the data; axial coding, comparing open codes with each other to create relevant categories; and selective coding, using frequently occurring axial codes to create core categories, or conceptual model domains (see Strauss and Corbin, 1990 for a full explanation of these coding processes).

Over an 18-month period, 13 steps were used in the coding and analysis process: (1) The interviews were video-recorded or audio-recorded and transcribed. (2) Each transcription was checked for accuracy. (3) At least two team members selected QoL-relevant text from each transcription. (4) The selected text was transferred to a spreadsheet along with its interview number. (5) Team members began coding text and generated a long list of codes (open coding). (6) The long list of codes was consolidated into categories (axial coding). (7) All selected text was coded with the axial codes. (8) The selected text was sorted by axial code and further consolidated into core domains (selective coding). (9) Draft items were written based upon the text comprising the core domains. (10) The number of draft items was reduced based upon participant, investigator, and parent judgment of the importance of items. (11) Draft items were "wordsmithed," maintaining original language as much as possible. (12) A reduced list of draft items was presented to an advisory board panel of community members, parents and clinicians. (13) A final set of items was cognitively debriefed with youth and prepared for field testing. Cognitive debriefing is a method by which individuals assess the relevance, importance, and comprehension of the content of measures (Fowler, 1993; Jabine, Stras, Tanor, & Tourangeau, 1984). Thirteen youth who are deaf or hard-of-hearing and who participated in the original interviews completed the draft instrument and afterward were asked to "think aloud" about how they interpreted each item and how they chose a response.





They were also asked to identify awkward or unclear wording, and to evaluate whether any important issues were not included.

Two types of items -- perceptual and contextual -- were developed for the YQOL-DHH. Perceptual items measure those aspects of QoL known only to the youth respondent, which cannot be observed by others. Contextual items are self-reported but are potentially verifiable or observable by others. Both types of items are considered important for assessing QoL (Cummins, 1997; Wallander, Schmitt, & Koot, 2001).

The original number of items generated was 351, all perceptual, distributed across 10 categories: (1) opportunities, (2) Belonging, (3) Adversity/Challenges, (4) Being treated badly, (5) Self-confidence, (6) Coping/self-efficacy, (7) Missing out, (8) Limitations, (9) Social support, and (10) Psychological distress. Although physical hearing issues were discussed by some youth interviewees, they were not included as a separate instrument domain as they are covered adequately by pre-existing instruments (as discussed above). The research team then evaluated each of these items and nominated the top 20 QoL items from each of the domains (self, social, environment) based upon the following criteria: (1) the item evaluated a "quality" (perception/sensation/feeling), (2) the item represented an area of importance to people with the condition, (3) the item was in the language of the youth with the condition, and the item was translatable conceptually, (4) the item was likely to change with successful treatment of the condition, (5) the item was likely to discriminate by severity of condition, (6) the item was likely to discriminate between known population groups, (7) the item was frequently mentioned by youth participants, and (8) the item was relevant to everyone with the condition. This resulted in 100 items that were retained and presented to each research team member for nomination of items that they thought best captured the QoL issues for youth who are deaf or hard-of-hearing. The reduced item list (N=54) was then presented to the advisory board panel for recommendation and selection. This process resulted in 42 perceptual items. These items were fielded in cognitive debrief interviews with DHH youth participants. Based on their input, the core research team selected the YQOL-DHH perceptual items for which verifiable items could be written to comprise a contextual set of 43 final items.

For a complete description of the process used in developing the YQOL-DHH, see Patrick et al (Patrick, et al. 2011).



1.7. Development of ASL DVD

Forward ASL translation of the survey items were completed by Drs. Kushalnagar and Schick, both fluent in ASL and English. Each forward translator uploaded videos to a secure website for the other forward translator to preview for consistency in choices of signed translation. On items that had different dialectical sign vocabulary, they met on videophone and discussed until an agreement on a translation was reached. After reconciliation of the two forward translators of the signed translation, two youth model signers were selected on basis of their ability to sign in ASL, level of interest in the project, and time availability.

The contracting video company provided editing and production work. All clips were reviewed and corrected by the research team fluent in ASL. Copies of DVDs were then mailed to the members for double-checking and accuracy prior to final production.



1.8. Response Scale

The YQOL instruments use an 11-point (0-10) rating scale with anchors outside the ends of the scale.

The response scales used with the perceptual items are:

Not at all | 0 1 2 3 4 5 6 7 8 9 10 | Very much

These response scales are based on the familiarity of the base 10 system and of rating things as “X...out of 10” in the common parlance of youth. Research indicates that discrimination among categories can improve up to 11-13 points, after which persons are unable to discriminate between numerical options (Nunnally, 1994). These response scales were tested with 6th to 12th grade students in the Seattle, Washington area. Students were asked to state their preference between 5-point Likert scales and the 11-point rating scales. Younger respondents preferred the 0-10 point scales, while older students were indifferent between the two options.





II. ADMINISTRATION

2.1. Mode of Administration

The YQOL generic and DHH-specific module is available in self-administered paper-and-pencil, and ASL-DVD.

The paper-and-pencil version was developed at a 4th grade reading level. A reading screener should be used in conjunction with the instrument to assess a 4th grade reading level.

The YQOL generic and DHH-specific module is available in an ASL DVD, which comes with an answer booklet for recording responses. Response options on the 11-point scale are not signed. The DVD version comes with specific directions on how to use the DVD in a computer or TV with DVD player.





III. SCORING INSTRUCTIONS

3.1. Description of the instrument

Dimensions	Number of Items	Item Reversal	Direction of Dimensions
Participation	10	Yes	Higher = higher QoL
Self-Acceptance/Advocacy	14	No	Higher = higher QoL
Perceived Stigma	8	Yes	Higher = lower QoL

3.2. Scoring of Contextual Items

The items comprising the YQOL-DHH instruments were written primarily based upon adolescent interviews. The adolescents' own words were preserved as much as possible in creating the items. There are two types of items in the instruments: 1) perceptual, or known only to the adolescent him or herself, and 2) contextual, or potentially verifiable by an outside observer. The perceptual items are primary in assessing QoL, as reflected in the WHOQOL Group definition regarding "perception of position in life". The contextual items are of secondary importance, but are especially useful for comparing the living conditions of disparate population sub-groups. It is our position that ideally both types of items be used together to comprehensively assess QoL.

Contextual items are on a 5-point Likert scale: items are scored from 0 (Never) to 4 (Very Often). The adjectives used in the Likert scale are intended to be equidistant from each other; however, we have not conducted research to date to verify the equal-interval property of the response scale. Previous research indicates that this response scale, even if ordinal in measurement, can be used in summated ratings and treated as an interval scale. No domain or total scores are available for these contextual items.

Investigators are cautioned, however, that analyses should be conducted using parametric and non-parametric methods for verification of findings, given that these five point scales are not labeled numerically nor have respondents been instructed to treat them as equal interval.



3.3. Scoring of Perceptual Domains

Item scaling	Perceptual Items are on an 11 point rating scale: items are scored: <i>Not at all</i> 0 1 2 3 4 5 6 7 8 9 10 <i>Very much</i>
Range of scores	The scores per domain are transformed on a scale from 0 to 100. For all domains a higher score indicates a better quality of life.
Scoring procedure	After transformation of the item scores, domain scores are calculated by computing the mean for the items that comprise each scale. A minimum of 80% of items in the scale must be non-missing to compute a scale score. For Participation domain, at least 8 of 10 items have to be answered. For Self-Acceptance/Advocacy domain, at least 12 of 14 items have to be answered. For Perceived Stigma domain, at least 7 of 8 have to be answered.
Interpretation and Analysis of Missing Data	Missing data should be reviewed to verify that data are missing at random. Youth with non-random missing data should be eliminated from further analyses. Information regarding the association of missingness with demographic and other variables should be reviewed and noted as a limitation in the analysis.

3.4. Scoring Syntax

3.4.1. SPSS Syntax for Transforming Scores to 100-Point Scale

Prior to calculating the domain scores, items are first transformed to a 100-point scale. The following syntax can be used in SPSS 13.0 or higher. Because variable labels are longer than eight characters, this syntax will not work with earlier versions of SPSS.

```
DATA NEW;  
SET youth1;  
label  
hqlp1aT='Things to do with others'  
hqlp2aRT='Left out of family conversations'  
hqlp3aT='Fit in with family'  
hqlp4aT='Accepted by students'  
hqlp5aT='Included in family'  
hqlp6aRT='Life is harder'  
hqlp7aRT='Work harder'  
hqlp8aRT='Hard to understand others'  
hqlp9aT='Easy to talk to people'
```





```
hqlp10aRT='Hard to participate in groups'
hqlp11aRT='Make fun of me'
hqlp12aRT='Bully me'
hqlp13aRT='Deaf treat me bad'
hqlp14aRT='Hearing treat me bad'
hqlp15aRT='Think I am dumb'
hqlp16aT='Satisfied with communication'
hqlp17aT='Enough technology'
hqlp18aT='Stand up for myself'
hqlp19aT='Ok ask for help'
hqlp20aT='Ask in public'
hqlp21aT='Tell teacher needs'
hqlp22aRT='Parents over protect'
hqlp23aRT='Future is limited'
hqlp24aT='Same independence as others'
hqlp25aRT='Miss out with hearing'
hqlp26aRT='Miss out with deaf'
hqlp27aRT='Miss out on activities'
hqlp28aRT='Miss what is important '
hqlp29aT='Youth help me'
hqlp30aT='Teacher helps me'
hqlp31aRT='Embarrassed when stared at'
hqlp32aRT='Others not understand me'
hqlp33aRT='Ask people to repeat'
hqlp34aRT='Others have Hard time communicating '
hqlp35aT='Explain I am DHH';
array part(10) hqlp2aRT hqlp6aRT hqlp7aRT hqlp8aRT hqlp10aRT
hqlp23aRT hqlp25aRT hqlp26aRT hqlp27aRT hqlp28aRT;
count_p=0;
do i=1 to 10; if part(i)>. then count_p=count_p+1; end;
array self(14) hqlp1aT hqlp4aT hqlp5aT hqlp9aT hqlp16aT hqlp17aT hqlp18aT
hqlp19aT hqlp20aT hqlp21aT hqlp24aT hqlp29aT hqlp30aT hqlp35aT;
count_s=0;
do i=1 to 14; if self(i)>. then count_s=count_s+1; end;
array Stigma(8) hqlp11aRT hqlp12aRT hqlp14aRT hqlp15aRT hqlp22aRT hqlp31aRT
hqlp32aRT hqlp33aRT;
count_t=0;
do i=1 to 8; if Stigma(i)>. then count_t=count_t+1; end;
if count_p>=8 then hqlp_part=MEAN(of hqlp2aRT hqlp6aRT hqlp7aRT hqlp8aRT
hqlp10aRT
hqlp23aRT hqlp25aRT hqlp26aRT hqlp27aRT hqlp28aRT);
else hqlp_part=.;
if count_s>=12 then hqlp_self=MEAN(of hqlp1aT hqlp4aT hqlp5aT hqlp9aT hqlp16aT
hqlp17aT hqlp18aT hqlp19aT hqlp20aT hqlp21aT hqlp24aT hqlp29aT hqlp30aT
hqlp35aT);
else hqlp_self=.;
if count_t>=7 then hqlp_pstigma=MEAN(of hqlp11aRT hqlp12aRT hqlp14aRT hqlp15aRT
hqlp22aRT hqlp31aRT hqlp32aRT hqlp33aRT);
else hqlp_pstigma=.;
label
hqlp_part   = "Participation"
hqlp_self   = "Self Acceptance & Advocacy"
hqlp_pstigma = "Stigma";
run;
```





IV. PSYCHOMETRIC PROPERTIES

Development of the YQOL-DHH perceptual module involved psychometric and practical testing to evaluate measurement properties, including conceptual and measurement model, reliability, validity, respondent and administrative burden, and alternative modes of administration. The adequacy of the hypothesized conceptual model was evaluated by examining evidence that: (1) the expected subdomains measured a single construct; (2) multiple scales measured distinct domains; and (3) the scale adequately represented variability in the domain.

4.1. Validation of the YQOL-DHH

The studies to validate the YQOL-DHH were conducted with approval from the institutional review boards at the University of Washington and Seattle Children's Hospital.

A multi-site observational study was conducted by investigators at the University of Washington (Seattle) and University of Colorado (Boulder). The sites partnered with Seattle Children's Hospital, Washington School for the Deaf, Arizona Schools for the Deaf, and other schools throughout the nation. Youths and at least one parent/guardian completed a battery of instruments (parent data are reported elsewhere).

4.1.1. Sample

The recruitment goal was 300 youth with a range of hearing loss (75 participants in each hearing loss category). The final sample obtained was 230 youth (Mild/Unilateral=27; Moderate/Mod-Sev=46; Severe/Profound=94; CI=63). Youth eligibility for participation in the study included having a hearing loss of more than 26 decibel (dB) and the ability to read English at least 4th grade level. Youth were excluded if their primary caregiver indicated that they had a co-morbid mental or physical condition that currently had a greater impact on their life than their hearing loss. Demographic characteristics of the sample are shown in Table 4.1.1. The sample was approximately 51% male, which is representative of youth with various degrees of hearing loss (Gallaudet Research Institute, 2006).





Table 4.1.1. Sample Characteristics by Degree of Hearing Loss

	Total Sample (n=230)	Mild/ Unilateral (n=27)	Mod/Mod- Sev (n=47)	Severe/ Profound (n=95)	CI (n=64)
MoC					
Sign	56	0	2	49	5
Speech	92	18	31	10	33
Sign/Speech	82	9	13	35	25
Parent					
Deaf/HOH	37	3	2	26	6
Hearing	193	24	44	68	57
Sex					
Male	118	14	29	44	31
Female	112	13	17	50	32
Ethnicity (4 missing)					
White	138	15	28	50	45
Hispanic/Latino	34	4	5	22	3
African American	15	2	5	6	2
Asian/Pacific Isl	7	2	0	4	1
Native American	9	1	2	4	2
Biracial/Other	23	3	4	7	9

Note. All data are presented as percentage of associated hearing loss group.

4.2. Domain Structure of the YQOL-DHH

During the item coding and analysis process described in Edwards et al. (2005), the research team sorted the items into ten a priori domains based upon the qualitative analysis. Quantitative evaluation of the individual items showed that three of the items differed significantly from the properties of a normal distribution and were subsequently eliminated. A review of the frequencies and ranges verified that all response choices were used, and that in general they followed a normal distribution. The cut-point adopted for floor/ceiling effects was greater than 66% of correspondents scoring in the top or bottom two response categories. The multi-trait/multi-item correlation matrix was used to examine the relationship of each item to its hypothesized scale and the other scales. A correlation of less than 0.4 was used to eliminate an item as not measuring the construct. Items correlating significantly higher to one of the competing scales than to its hypothesized scale were moved to the competing scale. Items within a scale with bivariate correlations greater than 0.7 were considered redundant and subject to elimination if the scale's integrity could be maintained without the item. Additionally, inter-scale correlations were computed to assess whether the scales uniquely contributed to the reliable variance in the data. Finally, items were assessed for greater than 5% missing data. We used cognitive debriefing reports (Jabine et al., 1984; Fowler, 1993) and advisory board experts opinion in making



final decisions on the elimination of items.

Based on the results of the multitrait/multi-item analysis, 3 items were eliminated because of either floor or ceiling effects. Additionally, the hypothesized domains were reduced from six to three, and twelve items were moved from their hypothesized domain to other domains with which they were more highly correlated.

The items were subjected to a principal components analysis (PCA) with a Promax rotation performed through SPSS for Windows Version 13.0 to confirm the hypothesized domain structure from the multitrait/multi-item analysis. The factor patterns and standardized regression coefficients indicated that the items grouped satisfactorily into the three hypothesized domains. Results of the principal components analysis (factor loading and communalities) are shown in Table 4.2.1 below. The three factor PCA model explained 59% of the observed variation. A single factor principal components analysis run on the three domain scores did not support the use of an overall score.



Table 4.2.1. Factor Analytic Structure of YQOL-DHH Perceptual Items

<i>Item stem: As a person who is deaf or hard-of-hearing...</i>		3 factor model		
Item # in final instrument	Abbreviated Item Content (see Table 2 for full item)	Self-Acceptance/ Advocacy	Perceived Stigma	Participation
1	Same independence as others	0.48	0.08	0.12
2	Included in family	0.42	0.11	0.20
3	Tell Teacher needs	0.67	0.16	0.02
4	Enough technology	0.44	0.21	0.09
5	Explain I am DHH	0.51	0.16	-0.02
6	Ok ask for help	0.62	0.09	0.08
7	Stand up for myself	0.53	0.17	0.16
8	Ask in public	0.65	-0.03	0.22
9	Easy to talk to people	0.35	-0.15	0.33
10	Satisfied with communication	0.52	0.10	0.22
11	Youth help me	0.48	0.27	-0.10
12	Teacher helps me	0.35	0.22	-0.28
13	Things to do with others	0.51	0.10	0.22
14	Accepted by students	0.48	0.41	0.17
15	Others not understand me*	0.35	0.50	0.39
16	Parents over protect*	0.14	0.38	0.16
17	Hearing treat me bad*	0.31	0.58	0.28
18	Think I am dumb* ‡	0.16	0.43	0.44
19	Bully me*	0.14	0.77	0.17
20	Make fun of me*	0.15	0.76	0.31
21	Embarrassed when stared at*	0.25	0.48	0.35
22	Ask people to repeat*	0.17	0.39	0.39
23	Left out of family conversations*	0.10	0.15	0.55
24	Miss out with deaf*	0.19	0.13	0.36
25	Miss out on activities*	0.20	0.24	0.54
26	Miss what is important*	0.17	0.22	0.61
27	Work harder*	0.04	0.26	0.67
28	Hard to participate in groups*	0.03	0.10	0.72
29	Future is limited*	0.26	0.18	0.38



30	Hard to understand* others	0.06	0.18	0.72
31	Miss out with hearing*	0.13	0.07	0.63
32	Life is harder*	0.08	0.24	0.64

†The three-factor solution was obtained by principal axis factoring orthogonal transformation with varimax rotation ($\kappa=4$).

*Item was reverse coded, with higher values signifying higher perceived stigma quality of life score.

‡Item loaded highest on Perceived stigma in promax rotation.





4.3. Reliability

The results of the analyses of internal consistency and reproducibility are shown in Table 4.1.1. The Cronbach's alphas and the intraclass correlations for the domains all exceeded the minimum requirement of 0.70 suggesting good internal consistency and reproducibility of the domain and overall scores.

4.1.1. Internal consistency and reliability

Table 4.1.1 Reproducibility and Internal Consistency of the YQOL-DHH

Domain	Number of Items	Cronbach α	Intraclass Correlation Coefficient (n=12)
Self-Acceptance/Advocacy	14	0.84	0.70
Perceived Stigma	8	0.85	0.78
Participation	10	0.86	0.92

4.2. Validity

4.2.1. Content validity

As described in the instrument development section, the content validity of the YQOL-DHH was aided by having youth themselves define the content of items. Additional items were elicited from parents of DHH children, deaf and hearing professionals working in deaf-related and reviews of the psychosocial literature involving children and youth who are deaf or hard-of-hearing.

4.2.2. Construct validity

Construct validity was tested using convergent, discriminant and know groups. Convergent and discriminant construct validity involve comparing logically related measures to see if they are correlated more strongly (convergent) or more weakly (discriminant) according to a priori expectations based on the content and theoretical relationships among constructs and their measures.

4.2.3. Convergent validity

For convergent we made the following a priori hypotheses: that a significant and higher correlation would be observed between the YQOL-DHH domains and the YQOL-R domains (measures of the same construct, i.e., perceived QoL), than





between self-rated health or the CDI total score (depressive symptoms) and the YQOL-DHH domains. The correlation of the YQOL-DHH with the YQOL-R compared to the correlation of the YQOL-DHH with self-rating of health and CDI was assessed using t-tests.

As anticipated, all scales of the YQOL-DHH correlated significantly with the scales of the YQOL-R indicating a significant association between the two measures of perceived QoL (see Table 4.2.3.1).

Table 4.2.3.1. YQOL Generic and YQOL-DHH Domain Correlations

YQOL-R Domains	Participation	Acceptance & Advocacy	Perceived Stigma
Self	.28*	.62*	.34*
Relationships	.32*	.67*	.36*
Environment	.27*	.52*	.29*

‡ $p < 0.05$, * $p < 0.01$.

4.2.4. Discriminant validity – known groups

For discriminant validity, we hypothesized that the correlations between self-rated health or depressive symptoms (measured with the Children's Depression Inventory, see Kovacs, 1992) would be lower than the correlations observed between the measures used for convergent validity. Another form of discriminant validity, known groups validity, was used to test the ability of the YQOL-DHH to discriminate between groups varying on known characteristics independent of or distal to the QoL measure. We conducted a multivariate analysis of covariance with the YQOL-DHH domains serving as dependent variables and with gender and age as covariates.

Pre-identified severity of hearing loss (mild, moderate, severe, profound) was the variable used to define known groups. It was hypothesized that youth whose hearing loss was more severe and who were mainstreamed in an inclusive setting would report lower QoL on all of the YQOL-DHH domains.



**Table 4.2.4.1a. Correlation of YQOL-DHH Domain Scores with Children's Depression Inventory Scores and PedsQL**

YQOL-DHH Subdomain Scores	Children's Depression Inventory (CDI)		<i>P value</i>
	CDI Score % ≤ Median† n=113	CDI Score % > Median† n=110	
<i>Self-Acceptance/ Advocacy</i>			
% ≤ Median	14.5%	35.3%	<i><0.0001</i>
% > Median	33.5%	16.7%	
<i>Perceived Stigma</i>			
% ≤ Median	34.6%	17.1%	<i><0.0001</i>
% > Median	11.4%	37.0%	
<i>Participation</i>			
% ≤ Median	13.6%	37.3%	<i><0.0001</i>
% > Median	34.1%	15.0%	

†Pearson chi square test

*p<0.05

**p<0.01

***p<0.0001

The assessment of QoL associated with hearing loss (Table 4.2.4.1b) examined the hypothesis that youth with more severe hearing loss would report poorer QoL. Tests of our hypotheses concerning differences between youth with milder form of hearing loss and those with more severe form of hearing loss were not supported. Contrary to our hypothesis, however, no significant differences between these groups were observed (see Table 4.2.4.1b). Statistically significant differences, however, were observed by gender on the perceived stigma and participation domains, but not on the self-acceptance/advocacy domain.





Table 4.2.4.1b. Means and Standard Deviations of YQOL-DHH Domains by Degree of Hearing Loss†

	Self-Acceptance/Advocacy (mean ± sd) (n=226)	<i>P value</i>	Perceived Stigma* (mean ± sd) [Geo Mean]‡ (n=215)	<i>P value</i>	Participation (mean ± sd) (n=226)	<i>P value</i>
TOTAL	75.46 ± 14.86		29.05 ± 20.33 [21.25]		75.46 ± 14.86 N=226	
AGE						
11-14 years (n=128)	76.91 ± 14.67		27.65 ± 20.66 [19.10]		65.05 ± 21.50	
15-18 years (n=97)	73.84 ± 14.81	NS	30.84 ± 19.98 [24.25]	P=0.05	52.12 ± 19.68	p=0.001
GENDER						
Female (n=116)	74.00 ± 14.92		31.08 ± 21.38 [22.52]		59.44 ± 21.62	
Male (n=112)	76.87 ± 14.72	NS	27.08 ± 19.14 [20.09]	NS	59.44 ± 21.72	NS
HEARING LEVEL						
Mild/Unilateral (n=26)	73.92 ± 16.47		30.61 ± 18.15 [25.21]		61.92 ± 22.92	
Mod/Mod-Severe (n=45)	77.68 ± 16.03		27.23 ± 20.42 [18.93]		59.28 ± 23.03	
Severe/Profound (n=94)	72.57 ± 15.09	p=0.07	31.10 ± 20.32 [23.57]	NS	58.67 ± 21.50	NS
Cochlear Implant (n=62)	78.39 ± 12.33		27.35 ± 21.25 [19.20]		59.35 ± 20.81	

†Analysis of Variance (ANOVA).

*Comparisons of the perceived stigma using normal mean excluded 0 values (obs=215). For Perceived Stigma domain, higher QoL scores are associated with greater perceived stigma.

‡Comparison of geometric mean of stigma used t-test. The overall comparisons used log regression procedure.

ANOVA models adjusting for age, gender, and hearing level were used to analyze possible differences in YQOL-DHH scores by mode of administration. No significant differences were observed for youth among the three modes of administration with sufficient sample size for analysis (paper-and-pencil n=119, web-based n=70, ASL OR PSE DVD self-administered n=20). Youth who completed the web-based or ASL or PSE DVD version however, reported significantly higher Participation scores than youth who completed the paper-and-pencil (see Table 4.2.4.1c).



**Table 4.2.4.1c..** YQOL-DHH Domain Scores by Mode of Administration†

<i>Completed mode of administration:</i>	Self-Acceptance/Advocacy (mean ± sd) (n=226)	Perceived stigma* (mean ± sd) [Geometric mean]‡ (n=210)	Participation (mean ± sd) (n=226)
<i>Paper & pencil</i> (n=119)**	75.63 ±15.35	29.97 ±20.61 [21.47]	57.25±22.18
<i>Web-based</i> (n=68)	78.24 ±12.77	22.77 ±20.44 [18.11]	64.09 ±19.21
<i>ASL or PSE</i> <i>DVD-self</i> (n=19)	72.58 ±15.30	26.51 ±14.45 [22.08]	66.27 ±19.90
	<i>p</i> =0.192	<i>p</i> =0.262	<i>p</i> =0.022

†Unadjusted Means and sd, the P-values are from ANOVA models adjusting for Age, Gender and Hearing Level

*Note: Comparisons based on a log transformation of the perceived stigma among N=210 youth
Perceived Stigma: Higher scores are associated with greater perceived stigma.

‡A log-transformation is applied to positive scores prior to model analysis, and adjusted geometric means are obtained by back-transformation.

4.3. Ability to detect change

At the time of preparation of this manual data were not available to assess the ability of the items to detect change. Please check with the authors for updates, as data collection and analyses are on-going to address this issue.





V. INTERPRETATION OF SCORES

5.1. Interpretation of high and low scores

The YQOL-DHH can be used to augment the results from the YQOL-R or as a stand-alone instrument. The YQOL-DHH has 3 domains which are interpreted by calculating a profile analysis. High scores (scores one standard deviation above the mean) on the positive domains of Participation and Self-Acceptance/Advocacy consequences indicate a relatively good quality of life, whereas high scores on the negative domain of Perceived Stigma indicate a relatively poor quality of life.

Scale	Number of items	Meaning of scores	
		Low	High
Participation	10	Poor Quality of Life	Good Quality of Life
Self-Acceptance/Advocacy	14	Poor Quality of Life	Good Quality of Life
Perceived Stigma	8	Good Quality of Life	Poor Quality of Life





VI. TRANSLATIONS

Language	Linguistic validation process					
	Forward Translation	Backward Translation	Adaptation	Clinician's Review	Cognitive Debriefing	International Harmonization
ASL	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



VII. CONDITIONS OF USE

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7.2. License/User agreement

USER AGREEMENT

Conditions for user of the Youth Quality of Life Instrument
Deaf and Hard-of-hearing Module (YQOL-DHH)

Date: _____, _____
Day Month Year

CONTACT INFORMATION

Name: _____

Agency/University/Company: _____

Title: _____

Full Address: _____

Country: _____

Phone: _____ Fax: _____

E-mail: _____

SUMMARY OF STUDY

- Title:
- Disease or disorder:
- Type of research
- Primary outcome measure or end point:
- Design:
- Number of expected respondents (total):
- Number of expected administrations of the questionnaires per respondent:
- Length of the follow-up (if any):
- Planned study date:
- Name of the funder:
- Other questionnaires used in the study:





IMPORTANT REMARK: THE YQOL-DHH MAY BE USED IN THE ABOVE MENTIONED INVESTIGATIONS WHEN THE FOLLOWING AGREEMENT IS COMPLETED AND SIGNED BY “USER”.

« _____(Person, University, Company)» referred hereinafter as « User » wishes to use the **YQOL-DHH** in the above mentioned versions.

The UNIVERSITY OF WASHINGTON distributes the **YQOL-DHH** and its translations available in the following languages: U.S. English and American Sign Language.

Therefore, User and UNIVERSITY OF WASHINGTON agree as follows:

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UNIVERSITY OF WASHINGTON shall deliver the original **YQOL-DHH** and/or the translations requested by “User” subject to the following conditions:

- The translations requested are available, and
- The present agreement is duly completed and signed by “User”

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2.1 No modification

“User” shall not modify, abridge, condense, adapt, recast or transform the **YQOL-DHH** in any manner or form, including but not limited to any minor or significant change in wordings or organization in **YQOL-DHH**, without the prior written agreement of UNIVERSITY OF WASHINGTON, which agreement shall not be unreasonably withheld or delayed.

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“User” shall not translate **YQOL-DHH**, without the prior written agreement of **Dr. Donald Patrick**.

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“User” shall not reproduce the **YQOL-DHH** except for the limited purpose of generating sufficient copies for use in investigations stated hereunder and shall in no event distribute copies of the **YQOL-DHH** to third parties by sale, rental, lease, lending, or any other profit-making means.

2.4. Publication

In case of publication of study results, “User” shall cite (1)





Donald L. Patrick, Todd C. Edwards, Anne M, Skalicky, Brenda Schick, Tari D. Topolski, Poorna Kushalnaga, Mei Leng, , Aprille M. O'Neill-Kem, Kathleen Sie. (2011). Validation of a quality of life measure for deaf or hard of hearing youth *J Otolaryn Head Neck*, in press

Provision of data

All data, results and reports obtained by, or prepared in connection with the **YQOL-DHH** shall remain the User's property. However, UNIVERSITY OF WASHINGTON may request the User to share data, results and reports obtained through the use of the **YQOL-DHH**, which request the User can accept or reject in its sole and unfettered discretion. UNIVERSITY OF WASHINGTON shall ensure the anonymisation of such data at three levels, by the removal of: any patient identification, any university or company identification and any therapy name. UNIVERSITY OF WASHINGTON will classify and reorganize such anonymous data and therefore, shall hold all intellectual property rights regarding these data when and if submitted to the data pool.

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2.5 Payment

2.5.1 Royalty fees (Authors)

The use of the **YQOL-DHH** is free of author's royalty fees.

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The use of the **YQOL-DHH** in studies is subject to a distribution fee payable to UNIVERSITY OF WASHINGTON, of an amount of 200 dollars for general and administrative expenditures plus 100 dollars per language version requested. This fee includes provision of a user manual and scoring program.

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2.5.3 Invoicing

For the use of the YQOL-DHH, at the time of execution of this agreement, "User" shall pay an amount of \$200 (two hundred dollars, US) for general and administrative expenditures plus \$100 (one hundred dollars, US) per language version and "User" shall pay such invoice within thirty (30) days of the date of this agreement.





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All and any information related to the **YQOL-DHH** including but not limited to the following: information concerning clinical investigations, creations, systems, materials, software, data and know-how, translations, improvements ideas, specifications, documents, records, notebooks, drawings, and any repositories or representation of such information, whether oral or in writing or software stored, are herein referred to as confidential information. Likewise, any information provided by User to **Authors** relating to this Agreement, including information provided in this Agreement, shall be treated as confidential information.

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5. Use of name

It is agreed that UNIVERSITY OF WASHINGTON shall not disclose, whether by the public press or otherwise, the name of “**User’ or institution**”, to any third party to this agreement except to the copyright holder(s) of the **YQOL-DHH**.





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6.2 In the scope of the use of the "Questionnaire"

Under no circumstances may Authors or UNIVERSITY OF WASHINGTON be held liable for direct or consequential damage resulting from the use of the YQOL-DHH.

6.3 In the event of non-renewal of this Agreement

In the event of non-renewal of this Agreement by UNIVERSITY OF WASHINGTON for any cause or failure by UNIVERSITY OF WASHINGTON to conclude a new agreement with "User" upon the expiry of this Agreement, UNIVERSITY OF WASHINGTON will have no liability for payment of any damages and/or indemnity to "User".

7. Term and termination

This agreement shall be effective as the date of its signature by "User" and shall continue for a term of 10 (ten) years at least or until the term of the study above mentioned in SUMMARY OF THE STUDY.

Either party may terminate this Agreement immediately upon providing written notice to the other party in the event of: (a) the other party's unexcused failure to fulfill any of its material obligations under this Agreement or (b) upon the insolvency or bankruptcy of, or the filing of a petition in bankruptcy or similar arrangement by the other party. User may terminate this Agreement for any reason upon 90 days written notice.

Upon expiration or termination of this Agreement UNIVERSITY OF WASHINGTON may retain in its possession confidential information it acquired from YQOL-DHH while under contract. The obligations which by their terms survive termination, include, without limitation, the applicable ownership, confidentiality and indemnification provisions of this Agreement, shall survive termination.

8. Assignment

This Agreement and any of the rights and obligations of "User" are personal to the "User" and cannot be assigned or transferred by "User" to any third party or by operation of law, except with the written consent of UNIVERSITY OF WASHINGTON notified to "User".





9. Separate Agreement

This Agreement holds for the above mentioned study only. The use of the **YQOL-DHH** in any additional study of the “User” will require a separate agreement **without additional fees, unless significant updates have been added to the user manual (new edition, etc.).**

10. Entire Agreement, Modification, Enforceability

The entire agreement hereto is contained herein and this Agreement cancels and supersedes all prior agreements, oral or written, between the parties hereto with the respect to the subject matter hereto.

This Agreement or any of its terms may not be changed or amended except by written document and the failure by either party hereto to enforce any or all of the provision(s) of this Agreement shall not be deemed a waiver or an amendment of the same and shall not prevent future enforcement thereof.

If any one or more of the provisions or clauses of this Agreement are adjudged by a court to be invalid or unenforceable, this shall in no way prejudice or affect the binding nature of this Agreement as a whole, or the validity or enforceability of each/and every other provision of this Agreement.

11. Governing law

This Agreement shall be governed by and construed in accordance with the laws of the State of Washington. Any disputes will be adjudicated first through the UNIVERSITY OF WASHINGTON and subsequently through courts in the State of Washington.

IN WITNESS WHEREOF, the parties hereto have caused this agreement to be executed by their duly authorised representatives as of the date first above written.

User/University/Company:

Name:

Title:

Signature:

Date:

UNIVERSITY OF WASHINGTON:

Name:

Title:

Signature:

Date:





7.3. Fees

Unit Price \$200.00 (\$25.00 for Students),

Additional Translations (\$100.00 each)

Electronic Shipping

- No cost

-

Standard Shipping & Handling

- USPS \$10

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USPS International Express (4-7 Business Days):

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- Australia: \$60
- Canada: \$30
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- Mexico: \$50
- South America \$60

7.4. Contact Information

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APPENDIX



Youth Quality of Life Instruments

Youth Quality of Life Instrument – Deaf and Hard-of-hearing Module (YQOL-DHH)

University of Washington
Department of Health Services
4333 Brooklyn Ave NE
Box 359455
Seattle, Washington 98195-9455
(800) 291-2193

NOTE: DO NOT REPRODUCE WITHOUT PERMISSION OF THE AUTHORS.



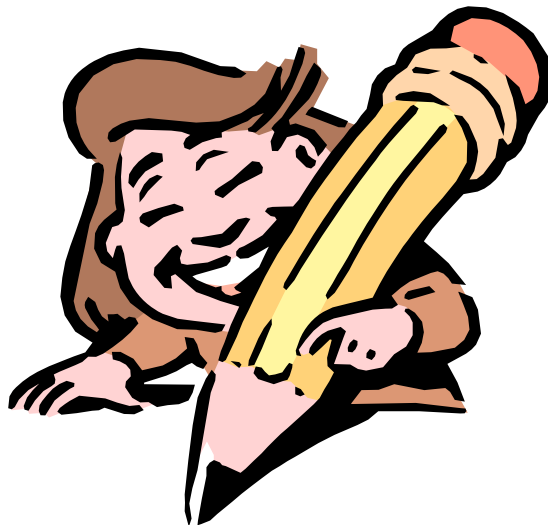
To all participants:

Many youths are taking part in this important survey. This survey will help us understand your thoughts and concerns so that better programs can be developed to improve the lives of youth who are deaf or hard-of-hearing.

The questions in this survey ask about a wide range of concerns and feelings. Some of these may or may not be important to you.

This is NOT a test, there are no right or wrong answers. Please answer as honestly as you can. Your responses will be kept strictly secret.

Thank you for your help!





Describing Your Life

Youth Ages 11-18



YQOL-DHH module



Project HQL
University of Washington
Department of Health Services
Seattle, Washington 98195-9455
(800) 291-2193

To all participants:

Many teenagers are taking part in this important survey. This survey will help us understand your thoughts and concerns so that better programs can be developed to improve the lives of teens who are deaf or hard-of-hearing.

The questions in this survey ask about a wide range of concerns and feelings. Some of these may or may not be important to you.

This is **NOT** a test. There are no right or wrong answers. Please answer as honestly as you can. Your responses will be kept strictly secret.

Thank you for your help!



How Does Your Hearing Affect Your Life

- You will read questions that ask how you feel about yourself and being deaf or hard-of-hearing.
- Please circle *ONE* answer that *BEST* describes how the question applies to you.
- There are no right or wrong answers.
- We are only interested in *HOW YOU FEEL ABOUT YOUR LIFE IN GENERAL*.

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The following items refer to the past 7 days....

During the *past 7 days*:

- | | | | | | |
|--|------------|-----------------------------------|-------------------------------|-----------------------|---|
| 1. How often were you left out of family conversations because you are deaf or hard-of-hearing?
<i>(please circle your answer)</i> | NEVER
0 | RARELY
(ONCE DURING WEEK)
1 | SOMETIMES
(2-3 TIMES)
2 | OFTEN
(DAILY)
3 | VERY OFTEN
(MORE THAN ONCE PER DAY)
4 |
|--|------------|-----------------------------------|-------------------------------|-----------------------|---|

During the *past 7 days*:

- | | | | | | |
|---|------------|-----------------------------------|-------------------------------|-----------------------|---|
| 2. How often have other people given up trying to understand what you were saying because you are deaf or hard-of-hearing?
<i>(please circle your answer)</i> | NEVER
0 | RARELY
(ONCE DURING WEEK)
1 | SOMETIMES
(2-3 TIMES)
2 | OFTEN
(DAILY)
3 | VERY OFTEN
(MORE THAN ONCE PER DAY)
4 |
|---|------------|-----------------------------------|-------------------------------|-----------------------|---|

During the *past 7 days*:

- | | | | | | |
|--|------------|-----------------------------------|-------------------------------|-----------------------|---|
| 3. How often did you do things together with your family?
<i>(please circle your answer)</i> | NEVER
0 | RARELY
(ONCE DURING WEEK)
1 | SOMETIMES
(2-3 TIMES)
2 | OFTEN
(DAILY)
3 | VERY OFTEN
(MORE THAN ONCE PER DAY)
4 |
|--|------------|-----------------------------------|-------------------------------|-----------------------|---|

During the *past 7 days*:

- | | | | | | |
|---|------------|-----------------------------------|-------------------------------|-----------------------|---|
| 4. How often was it difficult for you to understand conversations because you are deaf or hard-of-hearing?
<i>(please circle your answer)</i> | NEVER
0 | RARELY
(ONCE DURING WEEK)
1 | SOMETIMES
(2-3 TIMES)
2 | OFTEN
(DAILY)
3 | VERY OFTEN
(MORE THAN ONCE PER DAY)
4 |
|---|------------|-----------------------------------|-------------------------------|-----------------------|---|

During the *past 7 days*:

5. How often did you **miss something that anyone said** because you are deaf or hard-of-hearing?... *(please circle your answer)*

NEVER
0

RARELY
(ONCE DURING
WEEK)
1

SOMETIMES
(2-3 TIMES)
2

OFTEN
(DAILY)
3

VERY OFTEN
(MORE THAN
ONCE PER DAY)
4

During the *past 7 days*:

6. How often did you **use different ways to communicate** (texting, videophones, pagers and/or the internet) with people because you are deaf or hard-of-hearing?... *(please circle your answer)*

NEVER
0

RARELY
(ONCE DURING
WEEK)
1

SOMETIMES
(2-3 TIMES)
2

OFTEN
(DAILY)
3

VERY OFTEN
(MORE THAN
ONCE PER DAY)
4

During the *past 7 days*:

7. How often did you **quit trying when you did not understand** what someone was saying because you are deaf or hard-of-hearing?... *(please circle your answer)*

NEVER
0

RARELY
(ONCE DURING
WEEK)
1

SOMETIMES
(2-3 TIMES)
2

OFTEN
(DAILY)
3

VERY OFTEN
(MORE THAN
ONCE PER DAY)
4

During the *past 7 days*:

8. How often did you **get upset because you did not understand** what others were saying because you are deaf or hard-of-hearing? ... *(please circle your answer)*

NEVER
0

RARELY
(ONCE DURING
WEEK)
1

SOMETIMES
(2-3 TIMES)
2

OFTEN
(DAILY)
3

VERY OFTEN
(MORE THAN
ONCE PER DAY)
4

During the *past 7 days*:

9. How often did you **choose to be alone** and away from family activities because you are deaf or hard-of-hearing? ... *(please circle your answer)*

NEVER
0

RARELY
(ONCE DURING
WEEK)
1

SOMETIMES
(2-3 TIMES)
2

OFTEN
(DAILY)
3

VERY OFTEN
(MORE THAN
ONCE PER DAY)
4

THE FOLLOWING ITEMS REFER TO THE PAST 4 WEEKS....

During the *past 4 weeks*:

- | | | | | | |
|--|------------|----------------------------------|---|--------------------------------------|--|
| 10. How often did you spend time outside of school with people your age who are deaf or hard-of-hearing? ... <i>(please circle your answer)</i> | NEVER
0 | RARELY
(ONCE IN 4 WEEKS)
1 | SOMETIMES
(LESS THAN ONCE A WEEK)
2 | OFTEN
(AT LEAST ONCE A WEEK)
3 | VERY OFTEN
(MORE THAN ONCE A WEEK)
4 |
|--|------------|----------------------------------|---|--------------------------------------|--|

During the *past 4 weeks*:

- | | | | | | |
|--|------------|----------------------------------|---|--------------------------------------|--|
| 11. How often did you spend time outside of school with people your age who are hearing? ... <i>(please circle your answer)</i> | NEVER
0 | RARELY
(ONCE IN 4 WEEKS)
1 | SOMETIMES
(LESS THAN ONCE A WEEK)
2 | OFTEN
(AT LEAST ONCE A WEEK)
3 | VERY OFTEN
(MORE THAN ONCE A WEEK)
4 |
|--|------------|----------------------------------|---|--------------------------------------|--|

During the *past 4 weeks*:

- | | | | | | |
|--|------------|----------------------------------|---|--------------------------------------|--|
| 12. How often were you made fun of because you are deaf or hard-of-hearing?... <i>(please circle your answer)</i> | NEVER
0 | RARELY
(ONCE IN 4 WEEKS)
1 | SOMETIMES
(LESS THAN ONCE A WEEK)
2 | OFTEN
(AT LEAST ONCE A WEEK)
3 | VERY OFTEN
(MORE THAN ONCE A WEEK)
4 |
|--|------------|----------------------------------|---|--------------------------------------|--|

During the *past 4 weeks*:

- | | | | | | |
|--|------------|----------------------------------|---|--------------------------------------|--|
| 13. How often have you been bullied because you are deaf or hard-of-hearing? ... <i>(please circle your answer)</i> | NEVER
0 | RARELY
(ONCE IN 4 WEEKS)
1 | SOMETIMES
(LESS THAN ONCE A WEEK)
2 | OFTEN
(AT LEAST ONCE A WEEK)
3 | VERY OFTEN
(MORE THAN ONCE A WEEK)
4 |
|--|------------|----------------------------------|---|--------------------------------------|--|

During the *past 4 weeks*:

- | | | | | | |
|--|------------|----------------------------------|---|--------------------------------------|--|
| 14. How often did you ask someone to repeat what they said because you are deaf or hard-of-hearing?... <i>(please circle your answer)</i> | NEVER
0 | RARELY
(ONCE IN 4 WEEKS)
1 | SOMETIMES
(LESS THAN ONCE A WEEK)
2 | OFTEN
(AT LEAST ONCE A WEEK)
3 | VERY OFTEN
(MORE THAN ONCE A WEEK)
4 |
|--|------------|----------------------------------|---|--------------------------------------|--|

During the *past 4 weeks*:

- | | | | | | |
|--|------------|----------------------------------|---|--------------------------------------|--|
| 15. How often did others your age help you communicate because you are deaf or hard-of-hearing?...
<i>(please circle your answer)</i> | NEVER
0 | RARELY
(ONCE IN 4 WEEKS)
1 | SOMETIMES
(LESS THAN ONCE A WEEK)
2 | OFTEN
(AT LEAST ONCE A WEEK)
3 | VERY OFTEN
(MORE THAN ONCE A WEEK)
4 |
|--|------------|----------------------------------|---|--------------------------------------|--|

During the *past 4 weeks*:

- | | | | | | |
|---|------------|----------------------------------|---|--------------------------------------|--|
| 16. How often did you take part in activities outside of home or school with people who are deaf or hard-of-hearing ?... <i>(please circle your answer)</i> | NEVER
0 | RARELY
(ONCE IN 4 WEEKS)
1 | SOMETIMES
(LESS THAN ONCE A WEEK)
2 | OFTEN
(AT LEAST ONCE A WEEK)
3 | VERY OFTEN
(MORE THAN ONCE A WEEK)
4 |
|---|------------|----------------------------------|---|--------------------------------------|--|

During the *past 4 weeks*:

- | | | | | | |
|--|------------|----------------------------------|---|--------------------------------------|--|
| 17. How often did you did you take part in activities outside of home or school with people who are hearing ?... <i>(please circle one number)</i> | NEVER
0 | RARELY
(ONCE IN 4 WEEKS)
1 | SOMETIMES
(LESS THAN ONCE A WEEK)
2 | OFTEN
(AT LEAST ONCE A WEEK)
3 | VERY OFTEN
(MORE THAN ONCE A WEEK)
4 |
|--|------------|----------------------------------|---|--------------------------------------|--|

During the *past 4 weeks*:

- | | | | | | |
|---|------------|----------------------------------|---|--------------------------------------|--|
| 18. How often did you miss out on important information with people who are hearing ?... <i>(please circle one number)</i> | NEVER
0 | RARELY
(ONCE IN 4 WEEKS)
1 | SOMETIMES
(LESS THAN ONCE A WEEK)
2 | OFTEN
(AT LEAST ONCE A WEEK)
3 | VERY OFTEN
(MORE THAN ONCE A WEEK)
4 |
|---|------------|----------------------------------|---|--------------------------------------|--|

During the *past 4 weeks*:

- | | | | | | |
|---|------------|----------------------------------|---|--------------------------------------|--|
| 19. How often did you miss out on important information with people who are deaf or hard-of-hearing ?... <i>(please circle one number)</i> | NEVER
0 | RARELY
(ONCE IN 4 WEEKS)
1 | SOMETIMES
(LESS THAN ONCE A WEEK)
2 | OFTEN
(AT LEAST ONCE A WEEK)
3 | VERY OFTEN
(MORE THAN ONCE A WEEK)
4 |
|---|------------|----------------------------------|---|--------------------------------------|--|

During the *past 4 weeks*:

- | | | | | | |
|---|------------|----------------------------------|---|--------------------------------------|--|
| 20. How often did you get upset when others did not understand you because you are deaf or hard-of-hearing?... <i>(please circle one number)</i> | NEVER
0 | RARELY
(ONCE IN 4 WEEKS)
1 | SOMETIMES
(LESS THAN ONCE A WEEK)
2 | OFTEN
(AT LEAST ONCE A WEEK)
3 | VERY OFTEN
(MORE THAN ONCE A WEEK)
4 |
|---|------------|----------------------------------|---|--------------------------------------|--|

During the *past 4 weeks*:

21. How often did you **tell your teacher(s) what you need to help you learn** as a person who is deaf or hard-of-hearing?... *(please circle your answer)*

NEVER
0

RARELY
(ONCE IN 4
WEEKS)
1

SOMETIMES
(LESS THAN
ONCE A WEEK)
2

OFTEN
(AT LEAST
ONCE A
WEEK)
3

VERY OFTEN
(MORE THAN
ONCE A WEEK)
4

During the *past 4 weeks*:

22. How often did you **communicate for yourself in public places**?... *(please circle your answer)*

NEVER
0

RARELY
(ONCE IN 4
WEEKS)
1

SOMETIMES
(LESS THAN
ONCE A WEEK)
2

OFTEN
(AT LEAST
ONCE A
WEEK)
3

VERY OFTEN
(MORE THAN
ONCE A WEEK)
4

During the *past 4 weeks*:

23. How often did you **stand up or speak up for yourself when others made fun of you** because you are deaf or hard-of-hearing?... *(please circle your answer)*

NEVER
0

RARELY
(ONCE IN 4
WEEKS)
1

SOMETIMES
(LESS THAN
ONCE A WEEK)
2

OFTEN
(AT LEAST
ONCE A
WEEK)
3

VERY OFTEN
(MORE THAN
ONCE A WEEK)
4

ANSWER THE FOLLOWING QUESTIONS ONLY IF YOU HAVE BEEN IN SCHOOL IN THE PAST 4 WEEKS. IF YOU WERE NOT IN SCHOOL DURING THE PAST 4 WEEKS GO TO NEXT SET OF QUESTIONS ABOUT HEARING AIDS AND COCHLEAR IMPLANTS.

During the *past 7 days*:

24. How often was your teacher willing to give you enough help so that you could complete your school work?... (please circle your answer)
- | | | | | |
|------------|-----------------------------------|-------------------------------|-----------------------|---|
| NEVER
0 | RARELY
(ONCE DURING WEEK)
1 | SOMETIMES
(2-3 TIMES)
2 | OFTEN
(DAILY)
3 | VERY OFTEN
(MORE THAN ONCE PER DAY)
4 |
|------------|-----------------------------------|-------------------------------|-----------------------|---|

During the *past 4 weeks*:

25. In class, how often did you not know **what to do** because you are deaf or hard-of-hearing?... (please circle your answer)
- | | | | | |
|------------|----------------------------------|---|--------------------------------------|--|
| NEVER
0 | RARELY
(ONCE IN 4 WEEKS)
1 | SOMETIMES
(LESS THAN ONCE A WEEK)
2 | OFTEN
(AT LEAST ONCE A WEEK)
3 | VERY OFTEN
(MORE THAN ONCE A WEEK)
4 |
|------------|----------------------------------|---|--------------------------------------|--|

During the *past 4 weeks*:

26. In class, how often did you ask teachers, classmates or anyone for help to improve communication?... (please circle your answer)
- | | | | | |
|------------|----------------------------------|---|--------------------------------------|--|
| NEVER
0 | RARELY
(ONCE IN 4 WEEKS)
1 | SOMETIMES
(LESS THAN ONCE A WEEK)
2 | OFTEN
(AT LEAST ONCE A WEEK)
3 | VERY OFTEN
(MORE THAN ONCE A WEEK)
4 |
|------------|----------------------------------|---|--------------------------------------|--|

IF YOU ARE HARD-OF-HEARING, WEAR HEARING AIDS, OR HAVE A COCHLEAR IMPLANT, ANSWER THE FOLLOWING QUESTION. IF YOU DO NOT WEAR HEARING AIDS OR HAVE A COCHLEAR IMPLANT, PLEASE GO TO THE NEXT SET OF QUESTIONS ABOUT USING AN INTERPRETER.

During the *past 4 weeks*:

27. How often did you avoid a situation or place because it would be too noisy for you to understand what others are saying? ... (please circle your answer)
- | | | | | |
|------------|----------------------------------|---|--------------------------------------|--|
| NEVER
0 | RARELY
(ONCE IN 4 WEEKS)
1 | SOMETIMES
(LESS THAN ONCE A WEEK)
2 | OFTEN
(AT LEAST ONCE A WEEK)
3 | VERY OFTEN
(MORE THAN ONCE A WEEK)
4 |
|------------|----------------------------------|---|--------------------------------------|--|

IF YOU USE AN INTERPRETER IN SCHOOL, PLEASE ANSWER THE FOLLOWING QUESTION. IF YOU DO NOT USE AN INTERPRETER, PLEASE GO TO THE NEXT SET OF QUESTIONS ABOUT EVALUATING YOUR LIFE.

During the *past 4 weeks*:

28. How often did you miss
information in school **because you**
use an interpreter? ... (*please circle*
your answer)

NEVER
0

RARELY
(ONCE IN 4
WEEKS)
1

SOMETIMES
(LESS THAN
ONCE A WEEK)
2

OFTEN
(AT LEAST
ONCE A
WEEK)
3

VERY OFTEN
(MORE THAN
ONCE A WEEK)
4



Evaluating Your Life

- You will read questions that ask how you feel about yourself.
- Please circle *ONE* number on each scale that *BEST* describes how the statement applies to you.
- There are no right or wrong answers.
- We are only interested in how *YOU FEEL ABOUT YOUR LIFE IN GENERAL*.

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29. As a person who is deaf or hard-of-hearing, I **feel there are enough things** to do with people other than my family ... *(please circle one number)*

NOT AT ALL 0 1 2 3 4 5 6 7 8 9 10 VERY MUCH

30. Because I am deaf or hard-of-hearing, I **feel left out of family** conversations..... *(please circle one number)*

NOT AT ALL 0 1 2 3 4 5 6 7 8 9 10 VERY MUCH

31. As a person who is deaf or hard-of-hearing, I **feel accepted** by students at my school ... *(please circle one number)*

NOT AT ALL 0 1 2 3 4 5 6 7 8 9 10 VERY MUCH

32. I **feel included** in the things my family does together ... *(please circle one number)*

NOT AT ALL 0 1 2 3 4 5 6 7 8 9 10 VERY MUCH

33. I **feel life is harder** for me because I am deaf or hard-of-hearing ... *(please circle one number)*

NOT AT ALL 0 1 2 3 4 5 6 7 8 9 10 VERY MUCH

34. Because I am deaf or hard-of-hearing, I have to **work harder than other youth** to do the things I want to do ... *(please circle one number)*

NOT AT ALL 0 1 2 3 4 5 6 7 8 9 10 VERY MUCH

35. I feel it is **hard for me to understand** what people are saying because I am deaf or hard-of-hearing ... *(please circle one number)*

NOT AT ALL 0 1 2 3 4 5 6 7 8 9 10 VERY MUCH

36. As a person who is deaf or hard-of-hearing, it is **easy for me** to start talking to people I do not know ... *(please circle one number)*

NOT AT ALL 0 1 2 3 4 5 6 7 8 9 10 VERY MUCH

37. Because I am deaf or hard-of-hearing, I feel it is **hard to participate** in large groups ... *(please circle one number)*

NOT AT ALL 0 1 2 3 4 5 6 7 8 9 10 VERY MUCH

38. I feel **people make fun of me** because I am deaf or hard-of-hearing ... *(please circle one number)*

NOT AT ALL 0 1 2 3 4 5 6 7 8 9 10 VERY MUCH

39. I feel **people bully me** because I am deaf or hard-of-hearing ... *(please circle one number)*

NOT AT ALL 0 1 2 3 4 5 6 7 8 9 10 VERY MUCH

40. I feel people who are **hearing treat me badly** because I am deaf or hard-of-hearing ... *(please circle one number)*

NOT AT ALL 0 1 2 3 4 5 6 7 8 9 10 VERY MUCH

41. I feel **people think I am dumb** because I am deaf or hard-of-hearing ... *(please circle one number)*

NOT AT ALL 0 1 2 3 4 5 6 7 8 9 10 VERY MUCH

42. As a person who is deaf or hard-of-hearing, I am **satisfied** with the ways I have to communicate ... *(please circle one number)*

NOT AT ALL 0 1 2 3 4 5 6 7 8 9 10 VERY MUCH

43. I feel I **have enough** technology, such as pagers, videophones, texting, and/or internet to communicate as a person who is deaf or hard-of-hearing ... *(please circle one number)*

NOT AT ALL 0 1 2 3 4 5 6 7 8 9 10 VERY MUCH

44. I **know how to stand up or speak up for myself** as a person who is deaf or hard-of-hearing ... *(please circle one number)*

NOT AT ALL 0 1 2 3 4 5 6 7 8 9 10 VERY MUCH

45. As a person who is deaf or hard-of-hearing, I **feel okay asking** for help when I need it ... *(please circle one number)*

NOT AT ALL 0 1 2 3 4 5 6 7 8 9 10 VERY MUCH

46. As a person who is deaf or hard-of-hearing, I **feel okay asking** for what I want in public places ... *(please circle one number)*

NOT AT ALL 0 1 2 3 4 5 6 7 8 9 10 VERY MUCH

47. I **feel okay** telling my teacher about my needs as a person who is deaf or hard-of-hearing ... *(please circle one number)*

NOT AT ALL 0 1 2 3 4 5 6 7 8 9 10 VERY MUCH

48. I feel like my **parents protect me too much** because I am deaf or hard-of-hearing ... *(please circle one number)*

NOT AT ALL 0 1 2 3 4 5 6 7 8 9 10 VERY MUCH

49. Because I am deaf or hard-of-hearing, I **feel what I want to do in the future is limited** ... *(please circle one number)*

NOT AT ALL 0 1 2 3 4 5 6 7 8 9 10 VERY MUCH

50. As a person who is deaf or hard-of-hearing, I feel my parents **give me the same amount of independence** as others my age ... *(please circle one number)*

NOT AT ALL 0 1 2 3 4 5 6 7 8 9 10 VERY MUCH

51. Because I am deaf or hard-of-hearing, I feel I **miss things** when talking with **people who are hearing** ... *(please circle one number)*

NOT AT ALL 0 1 2 3 4 5 6 7 8 9 10 VERY MUCH

52. Because I am deaf or hard-of-hearing, I feel I **miss things** when talking with **people who are deaf or hard-of-hearing** ... *(please circle one number)*

NOT AT ALL 0 1 2 3 4 5 6 7 8 9 10 VERY MUCH

53. Because I am deaf or hard-of-hearing, I feel I **miss out on activities and things** I want to do ... *(please circle one number)*

NOT AT ALL 0 1 2 3 4 5 6 7 8 9 10 VERY MUCH

54. I feel I **miss what is important** for me to know because I am deaf or hard-of-hearing ... *(please circle one number)*

NOT AT ALL 0 1 2 3 4 5 6 7 8 9 10 VERY MUCH

55. I feel **other youth are willing to help me** when I need it as a person who is deaf or hard-of-hearing ... *(please circle one number)*

NOT AT ALL 0 1 2 3 4 5 6 7 8 9 10 VERY MUCH

56. **My teacher(s) helps me** to communicate easier in the classroom as a person who is deaf or hard-of-hearing ... *(please circle one number)*

NOT AT ALL 0 1 2 3 4 5 6 7 8 9 10 VERY MUCH

57. I feel **embarrassed when people stare** at me because I am deaf or hard-of-hearing ... *(please circle one number)*

NOT AT ALL 0 1 2 3 4 5 6 7 8 9 10 VERY MUCH

58. I **get upset** when people do not understand what I am saying because I am deaf or hard-of-hearing ... *(please circle one number)*

NOT AT ALL 0 1 2 3 4 5 6 7 8 9 10 VERY MUCH

59. I feel **embarrassed to ask** people to repeat themselves because I am deaf or hard-of-hearing ... *(please circle one number)*

NOT AT ALL 0 1 2 3 4 5 6 7 8 9 10 VERY MUCH

60. I **feel okay explaining** to others that I am deaf or hard-of-hearing ... *(please circle one number)*

NOT AT ALL 0 1 2 3 4 5 6 7 8 9 10 VERY MUCH

IF YOU ARE HARD-OF-HEARING, WEAR HEARING AIDS OR COCHLEAR IMPLANTS PLEASE ANSWER THE FOLLOWING QUESTIONS. IF YOU ARE NOT HARD-OF-HEARING, WEAR HEARING AIDS OR COCHLEAR IMPLANTS, PLEASE GO TO NEXT SECTION ABOUT USING AN INTERPRETER.

61. I **feel left out** in noisy situations or places because I am hard-of-hearing ... *(please circle one number)*

NOT AT ALL 0 1 2 3 4 5 6 7 8 9 10 VERY MUCH

62. I feel **lost in large groups** because it is hard to follow the conversation as a person who is hard-of-hearing ... *(please circle one number)*

NOT AT ALL 0 1 2 3 4 5 6 7 8 9 10 VERY MUCH

63. As a person who is hard-of-hearing, I feel like I **fit in with other youth who are deaf** ... *(please circle one number)*

NOT AT ALL 0 1 2 3 4 5 6 7 8 9 10 VERY MUCH

64. I feel like I **fit in with other youth who are hearing** because I am hard-of-hearing ... *(please circle one number)*

NOT AT ALL 0 1 2 3 4 5 6 7 8 9 10 VERY MUCH

***IF YOU USE AN INTERPRETER AT SCHOOL PLEASE ANSWER THE NEXT QUESTIONS.
IF YOU DO NOT USE AN INTERPRETER, GO TO NEXT SET OF QUESTIONS.***

65. I feel that having an interpreter at school **makes it hard for me** to talk with hearing kids ... *(please circle one number)*

NOT AT ALL 0 1 2 3 4 5 6 7 8 9 10 VERY MUCH

66. I feel I **have good interpreters** at school ... *(please circle one number)*

NOT AT ALL 0 1 2 3 4 5 6 7 8 9 10 VERY MUCH

IF YOUR PRIMARY MODE OF COMMUNICATION IS SIGN LANGUAGE, PLEASE ANSWER THE NEXT QUESTION. IF YOU DO NOT USE SIGN LANGUAGE, PLEASE GO TO THE NEXT SET OF QUESTIONS.

67. I **feel embarrassed** to sign in public ... *(please circle one number)*

NOT AT ALL 0 1 2 3 4 5 6 7 8 9 10 VERY MUCH

IF YOU HAVE HEARING MEMBERS IN YOUR FAMILY, PLEASE ANSWER THE NEXT QUESTION. IF YOU DO NOT HAVE HEARING MEMBERS IN YOUR FAMILY, PLEASE GO TO THE NEXT SET OF QUESTIONS.

68. I feel the hearing members of my family **try hard to communicate** with me as a person who is deaf or hard-of-hearing ... *(please circle one number)*

NOT AT ALL 0 1 2 3 4 5 6 7 8 9 10 VERY MUCH

About Yourself

The following questions ask for general information about you.

Please circle the number next to the option which best describes you.

Demographics, Self-Rated Health and CIPP Items (2002). Reprinted with Permission.

69. What is your sex? *(please circle one number)*

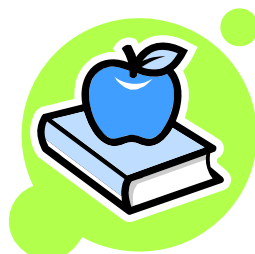
- 1 FEMALE
- 2 MALE

70. How would you describe your racial or ethnic background? *(please circle all that apply)*

- 1 CAUCASIAN
 - 2 HISPANIC
 - 3 AFRICAN AMERICAN
 - 4 ASIAN / PACIFIC ISLANDER
 - 5 NATIVE AMERICAN
 - 6 OTHER, PLEASE SPECIFY:
-



71. What was the last grade you finished in school? *(please circle one number)*



- 0 3RD GRADE
- 1 4TH GRADE
- 2 5TH GRADE
- 3 6TH GRADE
- 4 7TH GRADE
- 5 8TH GRADE
- 6 9TH GRADE
- 7 10TH GRADE
- 8 11TH GRADE
- 9 12TH GRADE
- 10 IN SCHOOL, BUT NO GRADE
- 11 GED
- 12 BEYOND HIGH SCHOOL
- 13 I'M NOT IN SCHOOL

72. How much school have your parents had?
(please circle the number for each parent)

MOTHER

FATHER

0	0	NO SCHOOL
1	1	PRIMARY SCHOOL (GRADES 1-8)
2	2	SOME HIGH SCHOOL
3	3	HIGH SCHOOL GRADUATE/GED
4	4	SOME COLLEGE
5	5	COLLEGE GRADUATE
6	6	DON'T KNOW

73. What is today's date? (please write-in your answer)

ENTER TODAY'S DATE HERE

_____/_____/_____
MONTH DAY YEAR

