PROBE-DHH

Deaf and Hard of Hearing

Module –

Parent Report of Observation of Behaviors and Events

User Manual and Interpretation Guide

1st Edition
2010

Seattle Quality of Life Group

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LIST OF ABBREVIATIONS

Abbreviation	Full text
PROBE	Parent Report of Observation of Behaviors and Events
DHH	Deaf and Hard-of-Hearing
SeaQoL	Seattle Quality of Life Group

INTRODUCTION

The Seattle Quality of Life Group at the University of Washington has worked for over the past 15 years assessing the quality of life among children who are often 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 with children with disabilities, chronic conditions, or who may for other reasons be marginalized by society.

This manual was designed to provide practical information on the *Deaf and Hard-of-Hearing Children Module – Parent Report of Observation of Behaviors and Events* (PROBE-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 *DHH PROBE Module*
- How it is administered
- Item characteristics
- How to calculate item scores
- Item test-retest reliabilities
- The available translations and linguistic validation methodology
- The conditions of use

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http://www.seaqolgroup.org

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I. INSTRUMENT OVERVIEW

1.1. History and development

The PROBE-DHH was developed by the SeaQoL Group with funding from the National Institute on Deafness and Other Communication Disorders and the Sie Foundation. The instrument development was conducted in two phases: Phase I item generation and selection (2007-2009); and Phase II statistical properties (2009-2010). The instrument was developed to assist clinicians and parents better understand observed behavior and events considered important for children with varying levels of hearing impairment and to be used in determining the need for appropriate interventions. The instrument was originally developed in US English and was culturally adapted to Mexican American Spanish and to American Sign Language. Version 1.0 of the PROBE-DHH was modified after Phase II data collection and Version 2.0 is included with this manual.

1.2. Instrument description

The PROBE-DHH is designed to assess observable behaviors and events considered important for children ages 5-10 years with acquired or congenital hearing impairment.

The PROBE-DHH contains items that are potentially verifiable only through external observation, and includes two age-specific versions : ages 5-7 years (n=9 items) and 8-10 years (n=8 items).

1.3. Instrument summary grid

Author(s)	*Donald L. Patrick, Todd C. Edwards, Anne Skalicky, Tari D. Topolski, Brenda Schick, Poorna Kushalnagar*
Stated Purpose of development	*Assessment of observable behaviors and events considered important for children with DHH*
Type of instrument	*DHH Module – Parent Report of Observation of Behaviors and Events*
Therapeutic area/Disease	*Congenital and Acquired Hearing Impairment*
Population/Age	*Children ages 5-7 and 8-10 years*
Domains	*None, individual indicator items only*
Number of items	5-7 years : 9 items 8-10 years : 8 items
Response scales	*5-point Likert scale*
Mode of administration	*Self-administered*
Time for completion	*Median time: 2 minutes for paper administration; xx minutes for DVD administration.*
Time recall	*Mixed between 7 days and 4 weeks*
Scoring	*Individual item means*
Existence of Normative data	*None currently available*
Language	*Original language: English* *Available translations: Mexican-American Spanish (Paper) and American Sign Language (DVD)*
Conditions of use	*Information on Copyright license agreement/fees*
Related website(s)	*http://www.seaqolgroup.org*

1.4. Background: Why A Module of Behaviors and Events?

Current estimates of hearing impairment from the Better Hearing Institute (Kochkin, 2005) indicate that approximately 31.5 million people (10.6%) people in the US are DHH. Severe to profound hearing impairment diagnosed in infancy or early toddlerhood is estimated to occur in 1 to 3 of every 1000 births and is thought to produce the most deleterious impact in the development of speech, language, and communication skills (see Greenberg & Kusche, 1989). Ninety-two percent of infants and children with hearing impairment have parents with normal hearing (Mitchell and Karchmer, 2003). Through its effect on the ability to communicate, socialize and cultural identity, hearing impairment poses enormous challenges to children and their families. The current literature available to families mainly focuses on how interventions enhance auditory abilities, speech, and language skills.

Well-designed research studies are needed to explicate the mechanisms by which the overall quality of life of children and youth with hearing impairment can be improved. Culturally, developmentally appropriate measures of outcome grounded in the populations affected by hearing impairment are needed for research studies and for evaluation of interventions.

Children and parents need reliable and relevant information with which to make important life choices. Parents and children report that the range of information available for use in making these choices is sorely limited. Parents typically make decisions (often with guidance and input from hearing professionals specializing in hearing impairment e.g., surgeons, teachers, audiologists, counselors) on the basis of potentially sensori-centric information (i.e., often solely from a hearing person's perspective without the consideration and sensitivity to the experience of deafness). This will not necessarily guide parents in the direction of fulfilling their primary desire to optimize well-being for their child with hearing impairment. Further, due to differences between the life experiences of hearing parents and children with hearing impairment, it may be difficult for the parent to fully understand what their child might define for him or herself as optimal experience.

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 children 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. Parent-child reporting agreement has been documented to be generally low, especially with regard to subjective perceptions such as quality of life and emotions (Phipps et al., 1999; Waters et al 2003; Theunissen et al 1998). Therefore, when parent

measures are considered to be proxy measures for child perceptions, they must be regarded with great suspicion. Nevertheless, parents are the principal decision makers for the young child's well-being, including use of aids (e.g., cochlear implants), school type (residential, private, and public) and communication style (Aural vs. Visual). Thus understanding parents' perceptions of their children's behaviors and events in regard to hearing impairment is important. Parent perceptions may be measured without considering them proxy reports, similar to caregiver measures used with adult populations (Patrick and Erickson, 1993).

Two modules were 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-DHH Manual) and reporting of observable behaviors and events considered important for children ages 5 to 10 years (PROBE-DHH).

1.5. Development of the PROBE-DHH

A conceptual model and qualitative methodology developed for the generic- Youth Quality of Life (YQOL-R) research instrument guided the creation of the PROBE-DHH module (Edwards et al, 2002; Patrick et al., 2002). The YQOL-R incorporates the three principal domains of Sense of Self, Social Relationships and Environment hypothesizing that the effects of social relationships and environment are mediated by the outlook of the individual (Edwards et al., 2002). During the development of PROBE-DHH, we used Doyal and Gough's conceptualization of characteristics of needs which apply to all cultures as a final criterion for selecting PROBE-DHH items (Doyal & Gough, 1991; Edwards et. al, 2002).

In developing the PROBE-DHH, 46 semi-structured, in-depth interviews with parents of children ages 5-10 years with a range of congenital and acquired hearing impairment 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 parents 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 parent interviews to a manageable amount.

Parents were purposively selected to represent a broad range of their children's hearing impairment: (1) mild (n=3); (2) moderate (n=5); (3) moderate-severe (n=9); (4) severe (n=7); (5) profound/CI (n=20). The main objective of this sampling approach was to articulate a diverse set of parental reports and observations regarding important behaviors and events among children who are deaf or hard of hearing and present with diverse communication preference and educational backgrounds.

The parents of children (ages 5 to 10) were approached to participate in the research project as "expert informants" to help design a questionnaire that ask about observable behaviors and events among children who are deaf or hard of hearing. 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 parents who are deaf and use American Sign Language as their primary language. Two parent interviews were conducted in Spanish with a researcher who is fluent in this language. Interviewees were recruited until what they were telling us became redundant with what previous interviewees had said and little new information was gained.

Parent interviewees were invited to generally discuss their children's lives in relation to others their age, including observable behaviors and events that are thought to impact quality of life as deaf or hard of hearing children. Specific probes were used to illuminate stage-salient contexts of children's observable behaviors and events home, school, work, and community (Bronfenbrenner,

1979), and how these behaviors and events may be impacted by their hearing impairment in today society.

We generated an item pool from qualitative interviews with parents of children with a wide range of hearing impairment, and input from clinicians working with deaf and hard of hearing children. 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 impairment, anatomical variables, and psychosocial maladjustment. We found no existing instruments that reflected a needs-level approach to parents' reports of important behaviors and events.

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, important behaviors and events of children who are deaf or hard of hearing. It is an inductive process approach, with an emphasis on social dynamics. The basic tenet of symbolic interactionism is that people construct meanings about their lives on the basis of interactions they have with other people and the world at large.

The investigators, previously experienced in this approach (Edwards, Huebner, Connell, & Patrick, 2002), worked with the transcribed interviews to code relevant issues and to write items based as closely as possible on the views and language of the participants 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 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 parents of

children ages 5 to 10 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). Twelve parents of children 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.

The original number of items generated was 772, all contextual, 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 parent 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 items from each of the domains (self, social, environment) based upon the following criteria: (1) the item evaluated observable behavior or emotion, (2) the item represented an area of importance to parents of deaf or hard of hearing children, (3) the item was in the language of the parent interviewee, 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 children by degree of hearing impairment, (6) the item was likely to discriminate between known population groups, (7) the item was frequently mentioned by parent participants, and (8) the item was relevant to all children who present with varying levels of hearing impairment. This resulted in 88 items that were retained and presented to each research team member for nomination of items that they thought best captured the behaviors and events as exhibited by children who are deaf or hard of hearing. The reduced item list (N=35) was then presented to the advisory board panel for recommendation and selection. This process resulted in 22 contextual items. These items were fielded in cognitive debrief interviews with parent participants. Based on their input, the core research team selected the PROBE-DHH a contextual set of 22 final items. Final survey was pretested with 2 parents to determine whether the survey is of a suitable length to avoid participant burden.

1.7. Development of ASL DVD

Forward ASL translation of the survey items were done by Drs. Kushalnagar and Schick, both fluent in ASL and English. Each person uploaded videos to a secure website for the other team member 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 full agreement was reached by both team members for all signed translations, Dr. Kushalnagar proceeded with the next step of preparing item translations for the production. Dr. Topolski coordinated schedule and contract with a video production company. Dr. Kushalnagar, deaf since birth, was the model signer for the parent version of ASL DVD. The entire video session took approximately 3 days to complete.

The contracting video company provided editing and production work. All clips were reviewed and corrected via WebEx by the DVD team, consisting of the video production point-of-contact on contract, Drs. Kushalnagar, Topolski, Schick and Ms. Skalicky. Copies of DVDs were then mailed to the members for double-checking and accuracy prior to final production.

1.8. Development of a Spanish parent survey

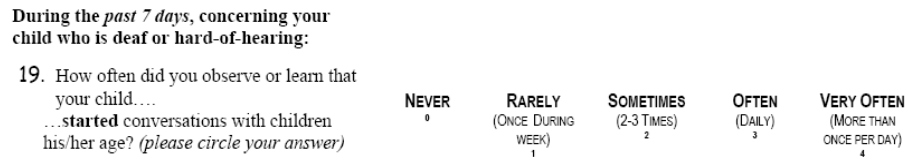
We produced a linguistic validation of the English parent questionnaire for 5-7 and 8-10 year old children. The Spanish parent survey is not a literal translation of the original instrument, but the production of a translation that is conceptually equivalent to the original and culturally acceptable to U.S. Spanish speakers.

Two bilingual, fluent translators produced an independent forward translation of the original English PROBE-DHH instrument's instructions, items and response choices into U.S. Spanish.

A team of translators and project co-investigator reconciled translation discrepancies to create a final and forward translation. The aim of the forward translation was to produce a conceptually equivalent Spanish version of the original questionnaire. This language should also be colloquial and easy to understand. An independent bilingual translator then conducted a back translation from the Spanish forward translation to English (blinded to the original English text). This final process was then reviewed between forward translators and project co-investigator to produce the second reconciliation of the forward translation of the original survey into Spanish.

1.9. Response Scales

The PROBE-DHH items are on 5-point Likert scales with adjectival anchors on each of the five responses. Likert scales are used widely in attitudinal research and in research with adolescents:



During the *past 7 days*, concerning your child who is deaf or hard-of-hearing:

19. How often did you observe or learn that your child….
…**started** conversations with children his/her age? *(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 adjectives used in this 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. 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.

II. ADMINISTRATION

2.1. Self-Administration guidelines

The PROBE-DHH should be self-administered in a quiet room, where privacy can be assured, and interruptions eliminated.

The DVD version can be self-administered if the parent respondent has access to a DVD player on TV or personal computer.

2.2. Example of introductory speech

When introducing the participant to the instrument, the administrator should refer to the following script:

“Many parents 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 children 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!”

III. SCORING INSTRUCTIONS

3.1 Scoring of Items

The items are on a 5-point Likert scale, scored from 0 (“Never”) to 4 (“Very Often”). Scores consist of individual item means.

3.2. Scoring Syntax

IV. ITEM STATISTICAL PROPERTIES

Development of the PROBE-DHH module involved statistical 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.

Comment [t1]: HOW DO WE WANT TO HANDLE THIS HERE? EXPLAIN THE WHOLE HISTORY OF FACTOR ANALYSIS, ETC?

4.1. Validation of the PROBE-DHH

The studies to validate the PROBE-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 Children's Hospital and Regional Medical Center in Seattle, Washington School for the Deaf, Arizona Schools for the Deaf, New Mexico School for the Deaf, and other schools throughout the nation. Parent/guardian participants of children ages 5 to 10 and completed a battery of instruments.

4.1.1. Sample

The recruitment goal was 300 parents of children with a range of hearing impairment. The final sample obtained was 263 parents of children ages 5 to 10 (Hearing impairment in the **better ear**: Mild/High Frequency =23; Moderate/Mod-Sev=80; Severe/Profound=56; CI=104). Parent eligibility for participation in the study included having a child with hearing impairment of more than 26 decibel (dB) and the ability to read English at least 4th grade level. Parents were excluded if they reported that their children had a co-morbid mental or physical condition that currently had a greater impact on their life than their hearing impairment. Demographic characteristics of the sample are shown in Table 4.1.1. The sample was approximately XX% male, which is representative of children with various degrees of hearing impairment (Gallaudet Research Institute, 2006).

Comment [t2]: This can't be right, see table below.

Table 4.1.1. Sample Characteristics (n=271)

	N (%)
Age in Years	
5-7	126 (46%)
8-10	145 (54)
(mean ± sd)	7.57± 1.66
Gender	
Female	129 (48)
Male	141 (52)
Ethnicity	
Caucasian	192 (71)
Hispanic	44 (16)
African American	5 (2)
Asian/Pacific Islander	12 (4)
Native American	7 (3)
Other	10 (4)
Mother's Education	
Less than HS	12 (6)
HS/GED	19 (9)
Some College	63 (31)
College	111 (54)
Hearing Level	
Mild/Unilateral	26 (10)
Moderate/Mod-Sev	80 (30)
Severe/Profound	56 (21)
CI	104 (39)
Geographic Region	
West	131 (48)
Midwest	60 (22)
Northeast	11 (4)
South	69 (25)
School Type	
Mainstream without D/HH program	122 (45)
Mainstream with D/HH program	78 (29)
School for the deaf (day and residential)	65 (24)
Home School	6 (2)
Communication Method	
Speech	177 (66)
Sign	54 (20)
Equal Preference	38 (14)

Note. Sample sizes within characteristics may not sum to n = 271 due to missing values.

4.2. Domain Structure of the PROBE-DHH

During the item coding and analysis process, the research team sorted the items into ten a priori domains based upon the qualitative analysis.

Table 2. Descriptive and Test-Retest Statistics for DHH-PROBE Items by Age Group:

7-day Recall

	5-7 years (n=126)					8-10 years (n=145)				
Item	Mean	SD	% Floor	% Ceiling	ICC	Mean	SD	% Floor	% Ceiling	ICC
…had to try several ways to communicate with people to help them understand her/him? (hqlc6p)			26.98	9.52	0.69			27.59	10.35	0.64
…started conversations with children his/her age? (hqlc1p)	3.04	1.13	3.97	45.24	0.74	3.01	1.03	1.38	40.69	0.39
… spent time alone away from family activities because s/he is deaf or hard-of-hearing? (hqlc7p)			73.02	0.00	0.76			74.48	1.38	0.25
…participated in family conversations at meal times in the home? (hqlc3p)	3.33	0.98	2.38	57.14	0.70	3.41	0.80	0.00	57.24	0.44
…missed out on things that were said during family conversations because s/he is deaf or hard-of-hearing? (hqlc5p)			16.67	15.87	0.82			15.17	12.41	0.70
…tell you (or another parent) what went on during his/her day? (hqlc2p)	2.98	0.99	3.18	34.13	0.60	3.11	0.90	0.00	40.00	0.71
…had a hard time communicating with family members because s/he is deaf or hard-of-hearing? (hqlc4p)	N/A	N/A	N/A	N/A	N/A			26.90	8.97	0.80
…tell you (or another parent) that s/he is having a hard time because s/he is deaf or hard-of-hearing? (hqlc9p)			69.84	0.79	0.38			44.14	4.83	0.08

Table 3. Descriptive and Test-Retest Statistics for DHH-PROBE Items by Age Group:

28-day Recall

	5-7 years (n=126)					8-10 years (n=145)				
	Mean	SD	% Floor	% Ceiling	ICC	Mean	SD	% Floor	% Ceiling	ICC
Item	28-day recall									
…spent time enjoying him/herself with children his/her age outside of school? (hqlc19p)	2.88	1.16	4.76	38.89	0.73	3.06	1.03	0.69	44.83	0.54
…communicated comfortably with *children* outside the home? (hqlc11p)	3.23	1.04	1.59	55.56	0.69	3.15	1.02	0.00	51.72	0.62
…gave up on something that s/he wanted to do because of problems communicating? (hqlc21p)			53.18	6.35	0.65			50.35	4.14	0.67
…talked about his/her best friend? (hqlc13p)	2.78	1.35	9.52	43.65	0.48	2.68	1.36	13.10	36.55	0.69
…was left out of activities because s/he could not follow what was going on because s/he is deaf or hard-of-hearing? (hqlc22p)			49.21	0.79	0.46			42.07	3.45	0.66
…a lack of communication support limited your child's ability to participate in activities outside of school? (hqlc23p)			58.73	3.18	0.40			53.10	2.76	0.65
…communicated for him/herself outside of the home and school? (hqlc12p)	N/A	N/A	N/A	N/A	N/A	3.16	1.11	2.58	53.79	0.51
…participated in family conversations at large family gatherings? (hqlc14p)	2.85	1.43	6.35	46.83	0.62	2.82	1.22	2.76	34.48	0.30
…was bullied because s/he is deaf or hard-of-hearing? (hqlc17p)			87.30	0.00	0.53			75.17	2.76	0.38
…was made fun of because s/he is deaf or hard-of-hearing? (hqlc18p)			81.75	0.00	0.49			67.59	2.76	0.41
…got upset because s/he did not understand what others were saying? (hqlc20p)			26.98	8.73	0.43			24.14	7.59	0.50
…spoke up for him/herself as someone who is deaf or hard-of-hearing? (hqlc8p)	N/A	N/A	N/A	N/A	N/A	1.75	1.31	21.38	11.04	0.22
…participated in activities outside of school with other children who are deaf or	1.23	1.39	44.44	10.32	0.50	1.30	1.42	40.69	12.41	0.38

hard-of-hearing? (hqlc15p)										
…have to take over communication for your child outside of the home? (hqlc16p)	N/A	N/A	N/A	N/A	N/A			24.83	13.79	0.56

DROPPED

…communicated comfortably with *siblings*? (hqlc10p)	3.84	0.61	0.79	78.57	0.40	3.72	0.84	2.07	75.86	0.08

5-point response scale: never/rarely/sometimes/often/very often.

Items… were administered only to parents of DHH children ages 8-10 years.

Note about single and dropped items

Table 4. DHH-PROBE Item Scores by Age Group and Mode of Administration

	5-7 years (n=126)			8-10 years (n=145)		
	Paper & pencil	*Web*	*DVD-self*	*Paper & pencil*	*Web*	*DVD-self*
Item	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
	7-day recall					
…had to try several ways to communicate with people to help them understand her/him? (hqlc6p)				--	--	--
…started conversations with children his/her age? (hqlc1p)				--	--	--
… spent time alone away from family activities because s/he is deaf or hard-of-hearing? (hqlc7p)				--	--	--
…participated in family conversations at meal times in the home? (hqlc3p)				--	--	--
…missed out on things that were said during family conversations because s/he is deaf or hard-of-hearing? (hqlc5p)						
…tell you (or another parent) what went on during his/her day? (hqlc2p)	--	--	--			
…had a hard time communicating with family members because s/he is deaf or hard-of-hearing? (hqlc4p)	N/A	N/A	N/A			
	28-day recall					
…spent time enjoying him/herself with children his/her age outside of school? (hqlc19p)				--	--	--
…communicated comfortably with *children* outside the home? (hqlc11p)				--	--	--
…gave up on something that s/he wanted to do because of problems communicating? (hqlc21p)						
…talked about his/her best friend? (hqlc13p)	--	--	--			
…was left out of activities because s/he could not follow what was going on because s/he is deaf or hard-of-hearing? (hqlc22p)	--	--	--			
…a lack of communication support limited your child's ability to participate in activities outside of school? (hqlc23p)	--	--	--			

-- : denotes items with inadequate test-retest reliability

N/A: denotes items administered only to parents of 8-10 year olds

Table 5: Unadjusted DHH-PROBE Item Scores by Age Group and Sex

	5-7 years (n=126)			8-10 years (n=145)		
	Total	Female	Male	Total	Female	Male
Item	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
	7-day recall					
…had to try several ways to communicate with people to help them understand her/him? (hqlc6p)				--	--	--
…started conversations with children his/her age? (hqlc1p)				--	--	--
… spent time alone away from family activities because s/he is deaf or hard-of-hearing? (hqlc7p)				--	--	--
…participated in family conversations at meal times in the home? (hqlc3p)				--	--	--
…missed out on things that were said during family conversations because s/he is deaf or hard-of-hearing? (hqlc5p)						
…tell you (or another parent) what went on during his/her day? (hqlc2p)	--	--	--			
…had a hard time communicating with family members because s/he is deaf or hard-of-hearing? (hqlc4p)	N/A	N/A	N/A			
	28-day recall					
…spent time enjoying him/herself with children his/her age outside of school? (hqlc19p)				--	--	--
…communicated comfortably with *children* outside the home? (hqlc11p)				--	--	--
…gave up on something that s/he wanted to do because of problems communicating? (hqlc21p)						
…talked about his/her best friend? (hqlc13p)	--	--	--			
…was left out of activities because s/he could not follow what was going on because s/he is deaf or hard-of-hearing? (hqlc22p)	--	--	--			
…a lack of communication support limited your child's ability to participate in activities outside of school? (hqlc23p)	--	--	--			

Table 6: Unadjusted DHH-PROBE Item Scores by Age Group and Hearing Level

	5-7 years (n=126)				8-10 years (n=145)			
	Mild/ Uni (n=)	Mod/ Mod-Severe (n=)	Sev/ Prfnd (n=)	Coch Implant (n=)	Mild/ Uni (n=)	Mod/ Mod-Severe (n=)	Sev/ Prfnd (n=)	Coch Implant (n=)
Item	X (SD)	X (SD)	X (SD)	X (SD)	X (SD)	X (SD)	X (SD)	X (SD)
	7-day recall							
…had to try several ways to communicate with people to help them understand her/him? (hqlc6p)					--	--	--	--
…started conversations with children his/her age? (hqlc1p)					--	--	--	--
… spent time alone away from family activities because s/he is deaf or hard-of-hearing? (hqlc7p)					--	--	--	--
…participated in family conversations at meal times in the home? (hqlc3p)					--	--	--	--
…missed out on things that were said during family conversations because s/he is deaf or hard-of-hearing? (hqlc5p)								
…tell you (or another parent) what went on during his/her day? (hqlc2p)	--	--	--	--				
…had a hard time communicating with family members because s/he is deaf or hard-of-hearing? (hqlc4p)	N/A	N/A	N/A	N/A				
	28-day recall							
…spent time enjoying him/herself with children his/her age outside of school? (hqlc19p)					--	--	--	--
…communicated comfortably with *children* outside the home? (hqlc11p)					--	--	--	--
…gave up on something that s/he wanted to do because of problems communicating? (hqlc21p)								
…talked about his/her best friend? (hqlc13p)	--	--	--	--				
…was left out of activities because s/he could not follow what was going on because s/he is deaf or hard-of-hearing? (hqlc22p)	--	--	--	--				

…a lack of communication support limited your child's ability to participate in activities outside of school? (hqlc23p)	--	--	--	--				

Table 7. Correlation of DHH-PROBE Item Scores with Parent report of CDI Score MEI

	Children's Depression Inventory (CDI) Parent Report			Construct Validity Hypotheses and Results
	CDI Score ≤ Median n=	CDI Score >Median n=		
5-7 year olds	%	%	P value	
				•
8-10 year olds				
				•
				•
				•

Pearson correlations
Spearman rank correlations
*p<0.05
**p<0.01

V. INTERPRETATION OF SCORES

5.1. Interpretation of high and low scores

The PROBE-DHH can be used to augment the results from the YQOL-R parent report or as a stand alone instrument. The PROBE-DHH consists of individual items which are interpreted as individual indicators of behaviors and events considered important for children with hearing impairment.

VI. TRANSLATIONS

	Linguistic validation process					
Language	**Forward Translation**	**Backward Translation**	**Adaptation**	**Clinician's Review**	**Cognitive Debriefing**	**International Harmonization**
ASL	☑	☐	☑	☐	☐	☐
PSE	☑	☐	☑	☐	☐	☐

VII. CONDITIONS OF USE

7.1. Copyright

7.2. License/User agreement

USER AGREEMENT

Conditions for user of the Children Quality of Life Instrument Deaf and Hard of Hearing Module (PROBE-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**:
- **Number of countries/language versions involved:**

SPECIFY:

USA (Spanish) ☐, USA (English) ☐, UK (English) ☐,

IMPORTANT REMARK: THE PROBE-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 **PROBE-DHH** in the above mentioned versions.

The UNIVERSITY OF WASHINGTON distributes the **PROBE-DHH** and its translations available in the following languages: U.S. English, U.S. Spanish, and U.K. English.

Therefore, User and UNIVERSITY OF WASHINGTON agree as follows:

1. UNIVERSITY OF WASHINGTON's obligations

UNIVERSITY OF WASHINGTON shall deliver the original **PROBE-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"

2. "User's" obligations

2.1 No modification

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

2.2 No translation

"User" shall not translate **PROBE-DHH**, without the prior written agreement of **Dr. Donald Patrick**.

2.3 No reproduction

"User" shall not reproduce the **PROBE-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 **PROBE-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)

Provision of data

All data, results and reports obtained by, or prepared in connection with the **PROBE-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 **PROBE-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.

UNIVERSITY OF WASHINGTON may provide such reorganized data to third parties, for analysis in education, research, consulting, and specifically for the evaluation of cross-cultural equivalence and development of reference values for this PROBE-DHH or for any other similar project.

2.5 Payment

2.5.1 Royalty fees (Authors)

The use of the **PROBE-DHH** is free of author’s royalty fees.

2.5.2 Distribution fees (UNIVERSITY OF WASHINGTON)

The use of the **PROBE-DHH** in studies is subject to a distribution fee payable to UNIVERSITY OF WASHINGTON, of an amount of 150 dollars for general and administrative expenditures plus 100 dollars per language version requested. This fee includes provision of a user manual and scoring program.

The use of the **PROBE-DHH** in non-funded academic research in developing countries or by students is subject to a reduced price fee for the instruments and user manual.

2.5.3 Invoicing

For the use of the PROBE-DHH, at the time of execution of this agreement, “User” shall pay an amount of $150 (one hundred and fifty 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.

3. Copyright Infringement

The **PROBE-DHH** was developed by the Seattle Quality of Life Group at The University of Washington. The UNIVERSITY OF WASHINGTON holds copyright over the PROBE-DHH and all its present and future translations. Each new translation will be made available to third parties once it is available, through UNIVERSITY OF WASHINGTON, under the conditions described in the present document.

If, at any time during the term of this agreement, « User » learns of any infringement by a third party of any Intellectual Property Rights in connection with the **PROBE-DHH**, « User » shall promptly notify UNIVERSITY OF WASHINGTON. UNIVERSITY OF WASHINGTON shall notify such infringement to **Authors. Authors** will decide to institute or not proceedings against the infringing party.

4. Confidentiality

All and any information related to the **PROBE-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.

In consideration of the disclosure of any such confidential information to the other, each party agrees to hold such confidential information in confidence and not divulge it, in whole or in part, to any third party except for the purpose specified in this agreement.

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 **PROBE-DHH**.

6. Liability

6.1 In case of breach of contract

In the event of total or partial breach by UNIVERSITY OF WASHINGTON of any of its obligations hereunder, UNIVERSITY OF WASHINGTON's liability shall be limited to the direct loss or damage (excluding loss of profit and operating losses) suffered by "User" as a result of such breach and shall not include any other damages and particular consequential damages.

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 PROBE-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 **PROBE-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 **PROBE-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:	**UNIVERSITY OF WASHINGTON:**
Name:	Name:
Title:	Title:

Signature: Signature:

Date: Date:

7.3. Fees

Unit Price $150.00 ($25.00 for Students),
$200 YQOL + PROBE-DHH
Additional Translations ($100.00 each)

Electronic Shipping

- No cost
-

Standard Shipping & Handling

- USPS $10

U.S. Expedited Delivery:

▪ 1 day: $40 ▪ 2-day: $25

USPS International Express (4-7 Business Days):

▪ Africa/Asia $60
▪ Australia: $60
▪ Canada: $30
• Germany, Italy, France, UK: $50
• Mexico: $50
▪ South America $60

7.4. Contact Information

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VIII. BIBLIOGRAPHIC REFERENCES

APPENDIX