Youth Quality of Life Instruments

U.S. Version

User's Manual and Interpretation Guide

First Edition

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ACKNOWLEDGEMENTS:

The authors would like to acknowledge support to the University of Washington from the Centers for Disease Control and Prevention Cooperative Agreement No. U48/CCU009654 and from a contract awarded by Eli Lilly and Company for development of the Youth Quality of Life Instruments. Field testing of the YQOL surveillance instrument was made possible with the generous cooperation of Frank Mondeaux and RMC Research Corporation of Portland Oregon.

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PURPOSE OF THIS MANUAL

The purpose of this manual is to facilitate instrument administration, scoring, and interpretation of the YQOL-R, YQOL-S and YDS instruments.

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Suggested citation:

Topolski, T. D., Edwards, T. C., and Patrick .D L. (2002). User's manual and interpretation guide for the Youth Quality of Life (YQOL) Instruments. Seattle, WA: University of Washington, Dept. of Health Services.

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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:

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User/University/Company:	**UNIVERSITY OF WASHINGTON:**
Name:	Name:
Title:	Title:
Signature:	Signature:
Date:	Date:

WHY QUALITY OF LIFE?

Measures of mortality, morbidity, and behavioral risks are important in tracking health trends and in identifying social, cultural, and economic differences (Centers for Disease Control and Prevention, 1995). Such measures, however, do not provide the means for comparing the perceived well-being of different populations. Outcome measures that provide universal, comprehensive assessments of well-being are needed to complement diagnostic and clinical measures. A concept that meets these requirements is "quality of life" (QoL).

Quality of life (QoL) is an important concept that is "affected in complex ways by the person's physical health, psychological state, level of independence, social relationships, and the person's relationships to salient features of the environment" (WHOQOL Group, 1994). It has been defined as "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns" (Bonomi, Patrick, Bushnell, & Martin, 2000; WHOQoL Group, 1994). QoL defined this way is broader and more global than the concept of "subjective well-being" in reflecting the cultural and social context that defines *the good life* (Kahneman, Diener, & Schwartz, 1999, p. x).

The growing trend toward defining health more broadly than the absence of illness or disease has brought increased attention to QoL in pediatrics and adolescent medicine in recent years (Bullinger & Ravens-Sieberer, 1995; Drotar, 1998). This trend has been influenced by: advances in evidence-based medicine (Christakis, Davis, & Rivara, 2000) and an increasing cultural emphasis on the autonomy of youth that promotes self evaluation (Levine, 1995). Most studies assessing QoL among adolescents with chronic conditions use a narrow definition focused on aspects attributable to a particular condition (Wallander & Varni, 1998), or the slightly broader definition of functional status (Harding, 2001). These more narrowly focused measures are important in detecting small or disease-specific changes in a child's functioning (Levi & Drotar, 1998), but they are not adequate for the assessmint of perceived QoL across different conditions or among the general population. The desire to compare QoL and its determinants among different population subgroups, particularly vulnerable populations such as children and youth with chronic conditions and disabilities (National Institute on Disability and Rehabilitation Research, 1998) has served to promote QoL research.

A few measures of adolescent perceived QoL have been developed elsewhere, including Sweden (Lindstrom & Eriksson, 1993), Germany (Ravens-Sieberer & Bullinger, 1998), and Canada (Raphael, Rukholm, Brown, Hill-Bailey, & Donato, 1996), but a comprehensive measure for use in the USA has not been available previously.

DEVELOPMENT OF THE INSTRUMENTS

Theoretical Development

A grounded theory approach derived from the sociological theory of symbolic interactionism (Blumer, 1969) was used to guide the development of the YQOL conceptual model (Glaser & Strauss, 1967; Strauss & Corbin, 1990). This approach is used to model phenomena

about which little are known. It emphasizes social dynamics, and is an inductive process approach based on the basic tenet that people construct meanings about their lives based on interactions they have with other people.

Based on this approach, in-depth interviews, with a purposive sample of adolescents with and without disabilities ages 11-18, were conducted to assist in the development of the conceptual model and instrument items. Focus groups with adolescents, primary caregivers, and child health and welfare professionals were conducted. Existing instruments, used to assess adolescent health and well-being, were consulted as well.

The items comprising the YQOL instruments were written primarily based upon adolescent interviews, and secondarily upon existing instruments. 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 subgroups. It is our position that ideally both types of items be used together to comprehensively assess QoL.

The YQOL Instruments have been developed via a modular approach. There is a longer version designed for research and evaluation (YQOL-R), and a shorter version designed for population surveillance (YQOL-S). The YQOL-S is **not** intended, however, to be a representative short form version of the YQOL-R. It is, rather, a collection of individual social indicators of potential interest to policymakers. There are also plans for developing health condition-specific modules. A congenital and acquired facial anomalies module is currently being validated. The modular approach toward development is outlined in Figure 1 below.

The QoL definition adopted by the SeaQoL Group required that youth, themselves, define the important concepts and items. Additionally, it necessitated that the measure employ subjective self-report whenever possible, and that the items be developmentally appropriate. Additionally, the items were written primarily from a positive "glass half full" perspective, in order to counterbalance the deficit approach of assessment traditionally used.

	YQOL-S	YQOL-R	Scores
Group-Level			
Contextual	5 items	15 items	individual items
Perceptual	5 items	41 items	domain & total
Individual-Specific			
Perceptual	N/A	5 top areas	under development
Condition Specific	dependent upon particular module		
Facial Differences			
Facial Surgery	Under development		

Figure 1. YQOL Modular Development

Conceptual Model

The conceptual model presented in Figure 2 was derived via the grounded theory method. Interview data from 33 adolescents in the greater Seattle area, from various walks of life including mainstream, homeless, gay/lesbian, and those living with disabilities was analyzed. The interviews were audiotaped and transcribed verbatim for use in analysis. To help ensure that all relevant data were included in the analysis, at least two members of the research team (consisting of a sociologist, a pediatrician, a developmental psychologist, and a social psychologist) reviewed each interview and highlighted text that was relevant to the interviewees' concept of QoL.

The highlighted text, as well as information regarding the interview from which it was taken, was entered into a spreadsheet and distributed to pairs of team members for coding. Team members used three coding strategies: 1) *open coding* which is the assignment of codes to the text based on words or phrases that captured meaning in the data 2) *axial coding*, which compares open codes to each other to create relevant categories; and 3) *selective coding*, which uses frequently occurring axial codes to create core categories, or model domains (Strauss and Corbin, 1990).

The team members began open coding with a preliminary set of codes generated by one of the investigators' initial review of several interviews. Each team member added codes as necessary. All codes generated by this process were retained for analysis. Thus, a particular unit of text could have more than one code assigned to it by one or more coders. In this way, the unique perspective of each team member was preserved, and particular units of text were allowed to represent more than one concept. Such flexibility at this stage of coding was designed to allow for the emergence and assignment of as many relevant codes as possible, and was balanced by a consensus process whereby each analysis decision in axial and selective coding was reviewed and approved by each of the team members. New codes were compared to existing codes and consolidated when appropriate. The team worked by consensus to sort the open codes into a comprehensive list of categories via axial coding, and then to sort the axial codes into a conceptual model of QoL via selective coding.

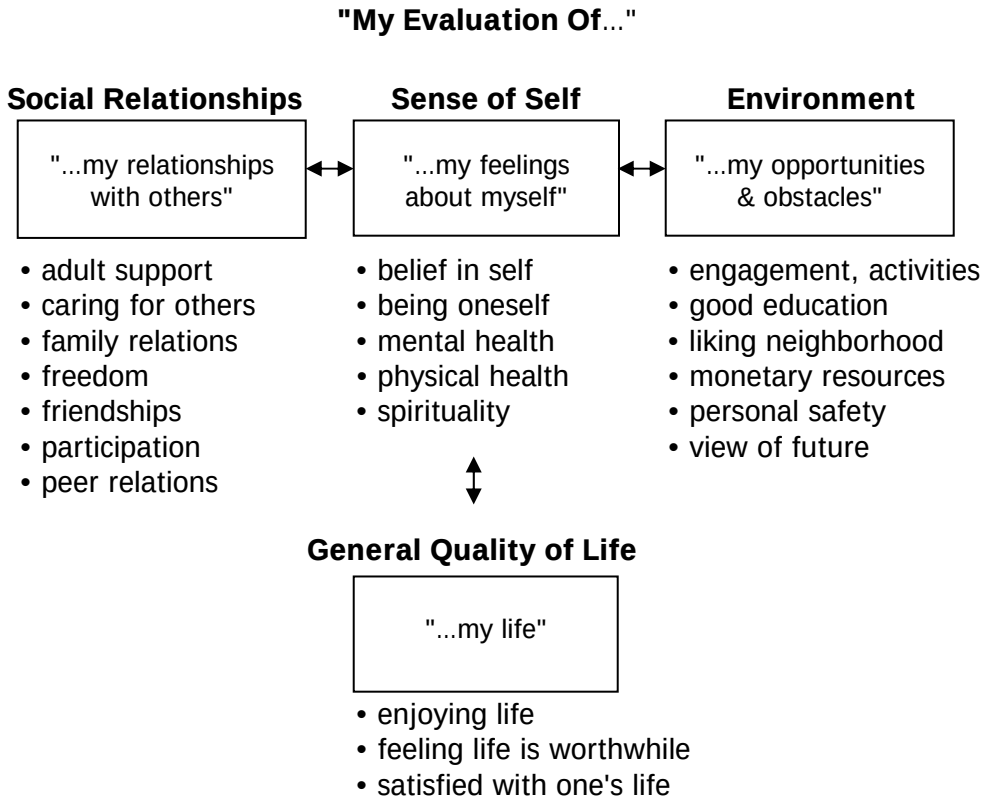

Figure 2. YQOL Conceptual Model

Response Scales

The YQOL instruments use two different types of response scales: 5 point Likert Scales with verbal anchors on each of the five responses and 11 point (0-10) rating scales with anchors outside the ends. Likert scales are used widely in attitudinal research and in research with adolescents. The response scale used most frequently in constructing the contextual items ("Describing Your Life" section) is a frequency mode as follows:

- Never
- Almost Never
- Sometimes
- Fairly Often
- Very Often

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.

The response scales used with the perceptual items are:

Not at all| 0 1 2 3 4 5 6 7 8 9 10 |*Completely*

Or

Not at all | 0 1 2 3 4 5 6 7 8 9 10 |*A great deal*

These response scales are based on the familiarity of the decimal system and of rating things as "...out of 10" in the common parlance of adolescents. 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 area. Students were asked to state their preference between 7-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.

For a complete description of the process used in developing the YQOL-R, see Edwards, et al., in press.

Instrument Validation

The studies to validate the YQOL-R and YQOL-S were conducted with approval from the institutional review boards at the University of Washington and Children's Hospital and Regional Medical Center in Seattle. Data from the various studies used in the validation of these instruments will be presented separately below.

YOUTH QUALITY OF LIFE INSTRUMENT - RESEARCH VERSION (YQOL-R)

The initial validation of the perceptual component of the YQOL-R followed established guidelines for measurement development (American Psychological Association, 1985; Medical Outcomes Trust, 1995; Nunnally, 1994), including conceptual and measurement model, reliability, validity, respondent and administrative burden, and alternative modes of administration.

Adolescents were recruited in the Seattle, Washington area from Children's Hospital and Regional Medical Center, community clinics for treating attention-deficit hyperactivity disorder (ADHD), adolescent health clinics at the University of Washington and other health care organizations, and through ads in local newspapers. Both parents/guardians and adolescents completed consent/assent forms. Parents gave formal written consent for the adolescents' physicians to release diagnostic and treatment information. Study group assignment was based on parental (or guardian) response to a telephone interview. The interview elicited the following information:

- age and grade in school
- ability to read English at the 6th grade level
- special classes at school
- history of physician diagnoses for depression, ADHD, or other mental health conditions
- past and current treatment for mental and physical health problems
- history of a disability lasting more than 6 months requiring the use of an aid or device for moving about the community

- history of any other long-term physical health problems
- assessment of which condition, in the case of more than one, presently had the greatest impact on the adolescent's life.

Adolescents meeting the age and reading criteria were assigned to the appropriate study cell based on the information derived from the parent. In cases where there were co-existing chronic conditions, the parent had to report that the target cell condition (ADHD or mobility impairment) was having the greatest current impact on the adolescent's life.

Participant Characteristics

The final sample for analysis included 236 adolescents (Table 1). Over a 12-month recruitment period, parents/guardians of 370 youth were screened. Of these, 236 met eligibility criteria, and returned consent forms. The predominately Anglo-American sample was ethnically similar to the population of the Seattle-King County area.

Table 1
Age, Sex and Ethnicity of Participants by Study Group

	Total Sample (n=236) %	**No Chronic Condition** (n=116) %	**ADHD** (n=68) %	**Mobility Disability** (n=52) %
Age				
12-14	33	36	46	12
15-18	67	64	54	88
Sex				
Female	30	41	0	44
Male	70	59	100	56
Ethnicity				
White	80	75	90	84
Asian/Pacific	7	12	0	4
African-American	5	5	4	4
Hispanic	1	0	0	4
Other/Mixed	8	8	6	4

Instrumentation

In validating the YQOL-R, data were collected with a variety of instruments to assess convergent and discriminant validity, including the assessment of differences in known groups. A brief description of the instruments and how they were used follows.

Clinician Diagnosis Verification Form. Clinicians were instructed to verify the presence or absence of: (a) clinical depression, (b) ADHD, (c) physical disabilities or chronic conditions, and (d) other physical or mental health diagnoses. For each condition, the clinician rated the severity of the condition on a 1 (normal, not ill) to 7 (very severely ill) scale, and indicated the types of treatment received for the condition.

Conners' Auxiliary ADHD/DSM IV Instrument – Adolescent Self-Report (CADS-A) (Conners, 1997) is a self-report symptom and behavior questionnaire designed to discriminate youth aged 12 to 17 with the psychiatric diagnoses of attention deficit, hyperactivity, and combined attention-deficit hyperactivity disorder as opposed to those with other psychiatric conditions or normals. The CADS-A was used for known groups/discriminant validation of the YQOL-R.

Children's Depression Inventory (CDI) (Kovacs, 1992), a self-report symptom oriented instrument designed to discriminate children and adolescents aged 7 to 17 with the psychiatric diagnosis of major depressive or dysthymic disorder as opposed to those with other psychiatric conditions or normals. The CDI was used in the analysis of convergent/discriminate validity. It was also used to control for depressed affect, which has been shown to have a significant negative correlation with quality of life (Goldney, Fisher, Wilson & Cheok, 2000).

Functional Disability Inventory (FDI) (Walker and Greene, 1991), designed for use with youth age 9 to 17, was used to assess ability of participants to perform daily activities, including sleep and rest, eating, home management, school, ambulation, mobility, and social interaction. The FDI provided another means for assessing known groups/discriminant validity.

Munich Quality of Life Questionnaire For Children (KINDL) (Ravens-Sieberer & Bullinger, 1998) assesses satisfaction with physical, psychological, social, and functional aspects of life. Developed in Germany, the KINDL is designed for youth ages 10-18 and a version in American English was incorporated here for testing of convergent validity.

The Youth Disability Screener (YDS) was developed by the research team as a short (4 item) self-administered screening instrument (Patrick, Connell, Edwards, Topolski, & Huebner, 1998) to identify adolescents with and without disabilities. We used this screener to confirm our disability recruitment category, and to test the ability of the YQOL-R to discriminate between participants with and without disabilities. See the YDS section below for a fuller explanation of the instrument.

Psychometric Evaluation

Development of the YQOL-R 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.

Poorly performing items in an instrument adversely affect the scale's ability to discriminate between different groups of respondents (e.g., "typical" adolescents vs. adolescents with disabilities), as well as diminish the chances of detecting important changes that result from treatment. A review of the frequencies and ranges verified that all response choices were used, and that they followed a normal distribution. The cut-point adopted for floor/ceiling effects was greater than 66% of respondents scoring in the top or bottom two response categories. The Multi-Trait/Multi-Item Analysis program (MAP) was used to investigate the scaling assumptions of the YQOL-R, including the total score and subscale scores that were derived from the measure (Hays et al., 1988; Ware, Harris, Gandek, Rogers & Reese, 1997).

The multitrait/multi-item correlation matrix was used to examine the relationship of each item to its hypothesized scale and the other scales. A correlation of <0.4 was used to eliminate items not measuring the construct. Items correlating significantly higher with one of the competing scales than with its hypothesized scale were moved to the competing scale. Items with a within scale bivariate correlation >0.7 were considered redundant and subject to elimination, if the integrity of the scale could be maintained. 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 >5% missing data. In addition to these psychometric properties of the items and scales, cognitive debriefing reports (Fowler, 1993; Jabine, Stras, Tanur, & Tourangeau, 1984) and investigator judgment were used in making final decisions on eliminating items.

Domain Structure of the YQOL-R

A principal components analysis with orthogonal varimax rotation of a four factor solution was used to test the a priori hypotheses of inter-relationships and the association of items to domains or “traits” (Hambelton and Slater, 1997). Additionally, a principal components analysis with a single factor was fit to the four domain scores to test the hypothesis of a total score.

Internal consistency

Cronbach’s Alpha was used to test internal scale consistency. A minimum coefficient of 0.70 was considered necessary for group comparisons.

Reproducibility

The reproducibility of the YQOL-R was examined by reviewing the data from 46 participants without chronic conditions who completed the YQOL-R instrument at baseline and again one week later. The intraclass correlation was used to assess the degree of reliability. An ICC > 0 .70 was considered necessary for group comparisons.

Content Validity

As described in the instrument development section, the content validity of the YQOL-R was aided by having adolescents themselves define the content of items. Additional items were elicited from adolescent health/welfare experts and reviews of the adolescent biomedical and psychosocial literature (Edwards, Huebner, Connell, & Patrick, in press).

Construct Validity

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. For convergent and discriminant validity, we made the following *a priori* hypotheses: that a significant and higher correlation would be observed between the KINDL and the YQOL-R (measures of the same construct of perceived QoL) than between the FDI (disability) or the CDI (depressive symptoms) and the YQOL. The correlation of the YQOL with the KINDL compared to the correlation between the YQOL and the FDI and CDI was assessed using t-tests.

Known Groups Validity

Another form of discriminant validity, known groups validity, was used to test the ability of the YQOL-R to discriminate between groups varying on known characteristics independent of or distal to the QOL measure. Depression and QoL have been shown to be significantly associated (Goldney et al., 2000). It has also been shown that adolescents with chronic conditions (such as epilepsy and severe acne) report higher levels of depression (Dunn, Austin, & Huster, 1999; Klassen, Newton & Mallon, 2000). Therefore, in our analysis of QoL, this association was taken into account.

Pairwise comparisons with Bonferroni adjustments were used to determine whether the YQOL-R could discriminate among adolescents who: 1) were recruited by study group with mobility disability, ADHD, or no chronic conditions, adjusted for the covariates age and depressive symptomatology, 2) reported depressive symptomatology based on a cut point of greater than or equal to 20 on the CDI, 3) reported ADHD symptoms based on a cut point of 16 or greater on the CADS-A, which is suggested to designate adolescents who are "at-risk" for ADHD, and 4) were with and without disabilities based on their self-report on the YDS which required a positive endorsement of one of four items regarding physical, emotional, or learning disabilities.

Item Reduction and Measurement Model

The original 49-item perceptual module fielded in the validation study was reduced to the 41 items shown in Appendix A on the basis of the multitrait/multi-item analyses and investigator judgment. Six items correlated <0.40 with their hypothesized scale, or correlated higher with at least two other scales, and tended to have positively skewed distributions. Two items were judged by the research team to have been poorly worded, and were eliminated. Based on the correlations between the scales and the items, two other items were moved to different scales. No items were eliminated solely because of floor or ceiling effects. One item, on which participants compared themselves with others their age, was taken out of the measure for use as a construct validation variable.

On the basis of the multitrait/multi-item analysis, two items were moved from their hypothesized domains to domains with which they were more highly correlated. After making this adjustment, the factor patterns and standardized regression coefficients indicated that the items grouped satisfactorily into the four hypothesized

domains. This model explained 53% of the observed variation. A single factor principal components analysis was run on the four domain scores to assess whether the data supported the use of a total score. The results of this analysis showed that this factor explained 80% of the total variation in the domain scores with an eigenvalue of 3.2, supporting the use of a total YQOL-R perceptual score. Item Response Theory will be used to evaluate the scales as soon as a large enough sample has been obtained.

Severity Ratings and Treatment Status of Participants

Diagnosis verification forms were received for 91% percent of the adolescents' from their primary physician. Diagnosis verification forms included an assessment of depression, ADHD, disability, and 'other' conditions. Among the group enrolled with their parent reporting no chronic conditions, physicians of 34 (29%) adolescents reported that the participant had some chronic condition, such as asthma, acne, allergies, enuresis, fatigue, or a stress-related condition. Physicians provided severity scores for 31 of these individuals with a mean rating of 1.94 (SD=1.03; 1=normal/not ill, 7=very severely ill). None of these participants were diagnosed with depression, ADHD, or mobility disability.

For the ADHD group, physicians provided ADHD severity ratings and treatment information for 62 out of 67 of the adolescents, and additional severity ratings for seven of these adolescents who had additional conditions. The mean ADHD severity rating among this group was 2.76 (SD=1.07). The chronic conditions for this group included allergies (n=1), learning disabilities (n=8), and thyroid problems (n=1) with a mean chronic condition severity rating of 3.80 (SD=1.62).

For 57 of the adolescents in the ADHD group, the physician reported that they were currently receiving treatment in the form of medication and six were receiving both medication and psychotherapy. Five physicians reported that the adolescent was not currently receiving treatment. The mean ADHD severity rating for these five adolescents was 3.20 (SD=1.30). Three of these adolescents scored as being at risk for ADHD on the CADS-A.

For the mobility disability group, 47 physicians completed the diagnosis verification form, with 45 providing severity ratings. Among those providing severity ratings, a diagnosis of birth defect was verified (e.g., spina bifida, cerebral palsy) for 30 adolescents, nine with para/quadriplegia, and two with breathing problems with a mean severity rating of 3.87 (SD=1.44). One adolescent in this group was also rated as having ADHD by his/her physician with a severity rating of 3.0. Only 35 physicians indicated treatment received by this group, with 33 currently receiving treatment. The mean severity rating for the group receiving treatment was 3.85 (SD=1.30).

Scores on the YQOL-R Perceptual Domains

Table 2 shows the YQOL-R estimated marginal mean scores (EMM) adjusted for age and CDI score, and 95% confidence intervals for the study groups by recruitment status. Participants in all groups scored highest on the Environment domain and lowest on the Self domain. To assess

differences between the groups, pairwise comparisons on the estimated marginal means were conducted applying a Bonferroni adjustment for multiple comparisons. The results of these analyses showed that the no condition group reported significantly higher (better) ratings than the ADHD group on all the domains, except General QoL and total perceptual YQOL-R score. Compared to the disability group, they also reported significantly higher ratings on everything except the Self domain. There were no differences in YQOL-R scores between the disability and the ADHD groups. In these analyses, age was included as a covariate; however, there was not a significant association between age and any of the perceptual domain scores in these data.

Table 2

Adjusted Mean Perceptual YQOL-R Domain and Total Score by Study Group

		EMM[a]	SE	CL	
	Group			**Lower**	**Upper**
Self	No Condition	**78.77**	1.28	76.26	81.29
	ADHD	72.72	1.65	69.48	75.97
	Disability	73.33	1.84	69.70	76.96
Relationship	No Condition	**80.79**	1.43	77.97	83.62
	ADHD	73.09	1.85	69.44	76.74
	Disability	73.96	2.07	69.88	78.04
Environment	No Condition	**87.56**	1.14	85.31	89.81
	ADHD	80.17	1.48	77.25	83.08
	Disability	79.21	1.65	75.96	82.47
General QoL	No Condition	**86.85**	1.58	83.74	89.95
	ADHD	79.87	2.04	75.86	83.88
	Disability	77.91	2.28	73.43	82.39
Total Perceptual Score	No Condition	**82.20**	1.14	79.95	84.45
	ADHD	75.19	1.48	72.28	78.09
	Disability	75.31	1.65	72.07	78.56

[a] Evaluated at covariates appearing in the model: AGE = 14.72, TOTCDI = 11.77.

Note: Means bolded are significantly higher at the $p < .05$ level than the means for the groups with name bolded. Bonferroni correction applied

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Based upon physician diagnosis verification, 29% of adolescents in the no-condition group had some sort of chronic condition (see above section). It was found that when these cases were removed, the results were unchanged. Therefore, these cases were retained in the analyses.

Only the no condition group had a sufficient number of females to allow comparisons by gender within group. A multivariate analysis of covariance (MANCOVA) revealed no significant differences on any of the YQOL-R perceptual domain scores by gender. Similarly, when we collapsed the data across groups there still were no significant mean differences by gender on these scales.

Internal Consistency and Reproducibility

The internal consistency reliabilities of the YQOL-R perceptual domains and total perceptual score are shown for the study groups (Table 3). Cronbach's alpha exceeded 0.77 for the four domains and total perceptual score for all study groups and the combined sample.

The correlation between the two instruments measuring the same construct (YQOL-R and KINDL) was compared to the correlation of the YQOL-R with the FDI and the CDI using a t-test for dependent correlations.

One-week test-retest data were collected only from adolescents without chronic conditions. The intraclass correlation coefficients for the five scales were as follows: Self (0.85), Relationships (0.85), Environment (0.76), General QoL (0.74), and Total Perceptual Score (0.78). These coefficients exceeded our criterion of 0.70 and were sufficient for group comparisons and comparable to reproducibility scores on other adolescent subjective measures such as the Revised Manifest Anxiety Scale (Reynolds & Richmond, 1985).

Table 3
Cronbach Alphas by Study Group for YQOL-R Perceptual Domain Scales

Domain	No Chronic Condition (n=116)	ADHD (n=68)	Mobility Disability (n=52)	Total Sample (n=236)	Number of Items in Scale
Self	.87	.88	.91	.88	14
Relationships	.89	.90	.90	.89	14
Environment	.81	.80	.81	.81	10
General QoL	.82	.77	.83	.81	3
Total Perceptual Score	.94	.94	.96	.95	41

Validation of the Construct

In general, all scales of the YQOL-R correlated highly with the scales of the KINDL, and the YQOL-R total perceptual score was correlated with the KINDL total score at 0.73 indicating a significant association between the two measures of perceived QoL

Two hundred twenty-nine of the participants provided complete information for these comparisons. The Pearson's correlation between the total YQOL-R perceptual score and the total FDI was -0.26, and -.58 with the CDI. The results of the t-test on the difference between these correlations showed that there is a significantly higher correlation between the YQOL-R and the KINDL than between the YQOL-R and the FDI (t_{226} = 6.61 $p < .05$). or the CDI (t_{226} = 3.66, $p < .05$).

In addition to known groups, the CADS-A, CDI, and YDS were used to determine whether the YQOL-R was sensitive to adolescents who reported real-time symptomatology. The data shown in Table 4 compare the mean YQOL-R perceptual domain and total scores for the study group as classified by the cut-points for depressive symptoms (CDI) and ADHD symptoms (CADS-A). YQOL-R perceptual scores were significantly lower for adolescents who scored above the depression and ADHD cut-points. Table 5 presents the data by disability status. Adolescents who self-reported that they had a disability scored significantly lower than adolescents who did not. These findings suggest that the YQOL-R is sensitive to current symptom status.

Table 4
Discriminant Validity Known Groups: YQOL-R Domain and Total Score Means and Standard Deviations by Depression and ADHD Screening Criteria

	Depression Cut-point[a]				ADHD Cut-point[b]			
YQOL-R domain	No (n=200) Mean (SD)	Yes (n=25) Mean (SD)	F[c]	p	No (n=200) Mean (SD)	Yes (n=34) Mean (SD)	F[c]	p
Self	78.3 (12.8)	54.9 (14.9)	70.6	.00	78.5 (13.3)	59.4 (14.8)	61.1	.00
Relationships	79.6 (14.1)	54.9 (18.0)	60.9	.00	79.7 (14.4)	60.4 (18.1)	50.5	.00
Environment	85.2 (11.7)	70.2 (17.7)	36.5	.00	85.6 (11.8)	71.9 (15.5)	35.4	.00
General QoL	85.7 (15.3)	58.5 (24.6)	58.0	.00	86.0 (15.7)	64.4 (22.9)	49.1	.00
Total	81.0 (11.7)	58.6 (14.2)	74.7	.00	81.1 (12.1)	63.2 (13.8)	64.4	.00

[a]CDI score greater than 20. [b]Raw score of 16 or more on the CADS-A ADHD index (the equivalent of a T-score of 60 or higher). [c]Test of between-subjects effects.

Table 5
Discriminant Validity Known Groups: YQOL-R Domain and Total Score Means and Standard Deviations by Disability Status

	Self-Reported Disability[a]			
YQOL-R domain	**No** (n=90) Mean (SD)	**Yes** (n=21) Mean (SD)	**F[b]**	**p**
Self	72.7 (11.4)	65.8 (12.2)	6.07	.02
Relationships	80.0 (13.3)	72.6 (15.9)	4.85	.03
Environment	85.1 (12.5)	84.4 (12.4)	0.06	.81
General QoL	82.2 (15.1)	71.2 (22.7)	7.28	.01
Total	79.1 (11.1)	73.4 (12.6)	4.24	.04

[a]A positive endorsement of one of four items regarding physical, emotional, or learning disabilities on the YDS. [b]Univariate results. The multivarite results showed that there was a significant difference (Wilks' lambda = .88, p = .01) between the groups on this set of means. The univariate results were then used to interpret where the groups differed.

YOUTH QUALITY OF LIFE INSTRUMENT - SURVEILLANCE VERSION (YQOL-S)

The YQOL-S was developed in concert with the YQOL-R as an instrument that could be used for monitoring QoL in the adolescent population. The items that comprise the YQOL-S were selected from the total pool of items in the YQOL-R based on their potential relevance for informing public policy, or in other words, what we judged were the items we would use if briefing the governor on adolescent QoL in the state. The YQOL-S has recently been revised from 5 perceptual items to 8 perceptual items to include the 3 items that comprise the General Quality of Life Scale from the YQOL-R.

Construct Validity

The YQOL-S total perceptual score has been shown to correlate .86 with the YQOL-R total perceptual score. The YQOL-S should NOT, however, be considered a short form of the YQOL-R since the items of the YQOL-S were not selected to be representative of the conceptual model underlying the YQOL-R.

Using the YQOL-S

The original 5 perceptual items of the YQOL-S along with 5 contextual items were fielded as part of a school-based study of health risk behaviors among adolescents (Topolski, et al., 2001). The contextual items fielded in the study, like the perceptual items, were chosen for their relevance to policy decision-makers. In addition to the YQOL-S, the YDS (see next section) was also fielded in this study.

Adolescents from middle schools and high schools participated in the study and provided information on health risk behaviors such as smoking, drinking, drug use, and engagement in sexually risky behaviors (e.g., multiple partners or unprotected sex). The demographics of the sample are shown in Table 6.

Table 6
Demographic Characteristics of YQOL-S School Sample

	Junior High (n=957) %	Senior High (n=1,809) %	Total (n=2,766) %
Female	47.6	49.1	48.2
Living with both biological parents	56.6	56.9	56.8
Ethnicity:			
White	69.8	72.9	71.2
Hispanic	11.5	8.7	9.6
Native American	5.7	5.1	5.4
Mixed/Other	10.0	11.6	11.0
Refused/Missing	3.0	1.7	2.8

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The YQOL-S perceptual items are located in Appendix D. Any of the 15 contextual items from the YQOL-R may be used in conjunction with the 8 items that comprise the YQOL-S perceptual domain, depending upon which items are most useful for the particular application.

In the paper by Topolski, et al. (2001), both contextual and perceptual items were scored individually and are presented in Table 7 below. In general, significant differences were found on the YQOL-S item between adolescents who were engagers in health risk behaviors and those who abstained from these behaviors.

In a paper by Edwards, Patrick, and Topolski (in submission), five contextual items were used as covariates in an analysis of covariance (ANCOVA). The purpose of this analysis was to determine whether there was a mean difference in total perceptual YQOL-S score between the groups after partialing out the variation that was attributable to the covariate contextual variables, self-rated health, depressive symptoms, and disability status to shed light on perceived quality of life differences between adolescents with and without disabilities.

Table 7
Mean Contextual and Perceptual Item Scores[d] by Health-Risk Behavior Group and Type of Risk

		Tobacco Mean (Std)	Alcohol Mean (Std)	Illicit Drugs Mean (Std)	Sexual Risk Mean (Std)
Missed Activity	**Abstainer**	91.42[c] (19.39)	91.87[bc] (19.26)	92.32[bc]	90.92[c] (19.74)
	Experimenter	89.89[c] (20.60)	89.80[ac] (20.89)	89.27[ac] (20.93)	90.25[c] (19.29)
	Engager	84.48[ab] (28.10)	85.28[ab] (27.58)	80.94[ab] (31.67)	81.99[ab] (32.45)
Conversation Adult	**Abstainer**	44.94 (33.73)	45.57 (33.59)	44.64 (33.31)	44.26[b] (32.97)
	Experimenter	44.65 (32.86)	45.23 (32.86)	45.53[c] (33.09)	51.45[ac] (33.75)
	Engager	42.27 (34.72)	39.54 (35.61)	38.63[b] (36.18)	38.21[b] (35.47)
Unwelcome	**Abstainer**	82.93 (27.27)	83.09 (27.85)	83.65[c] (26.72)	82.56 (27.21)
	Experimenter	82.51 (27.86)	82.20 (27.31)	82.29[c] (27.66)	84.56[c] (27.28)
	Engager	78.10 (32.09)	78.91 (32.61)	74.67[ab] (35.71)	75.44[b] (35.51)
Family argue	**Abstainer**	80.84[bc] (26.74)	82.23[bc] (26.68)	81.61[bc] (26.69)	76.99[c] (29.48)
	Experimenter	69.27[ac] (33.30)	72.73[ac] (30.84)	69.45[ac] (32.18)	71.04[c] (32.67)
	Engager	60.38[ab] (36.80)	59.52[ab] (38.35)	57.61[ab] (39.64)	59.61[ab] (38.62)
Blues	**Abstainer**	82.66[bc] (28.39)	85.75[bc] (25.87)	85.74[bc] (25.43)	80.80[c] (29.20)
	Experimenter	77.81[ac] (30.46)	76.06[a] (31.60)	73.51[a] (32.36)	75.0[c] (33.31)
	Engager	65.58[ab] (36.30)	70.56[a] (35.57)	67.31[a] (38.20)	66.59[ab] (36.69)
Get along parents	**Abstainer**	81.0[bc] (28.25)	81.89[bc] (28.44)	81.77[bc] (27.38)	77.03[c] (29.23)
	Experimenter	71.50[ac] (29.03)	74.92[ac] (27.91)	72.63[ac] (27.98)	75.54[c] (26.34)
	Engager	60.74[ab] (34.03)	59.64[ab] (35.46)	54.56[ab] (37.51)	59.37[ab] (37.58)
Forward to future	**Abstainer**	87.44[c] (22.96)	87.17[c] (22.90)	88.03[c] (21.42)	85.88[c] (23.66)
	Experimenter	82.33[c] (27.18)	84.56[c] (25.48)	83.79[c] (25.08)	85.25[c] (25.72)
	Engager	73.24[ab] (34.38)	72.71[ab] (34.80)	65.03[ab] (40.33)	66.14[ab] (38.81)
Alone in life	**Abstainer**	74.56[c] (32.32)	75.54[b] (32.40)	74.37[b] (32.68)	71.58 (32.50)
	Experimenter	67.99[c] (33.01)	67.80[a] (33.11)	66.38[a] (33.18)	76.94[c] (30.69)
	Engager	62.98[ab] (35.42)	68.84 (35.00)	69.23 (35.25)	60.21[b] (37.83)
Good about self	**Abstainer**	81.02[bc] (25.45)	83.49[bc] (24.25)	81.72[bc] (24.31)	77.88[c] (26.20)
	Experimenter	73.46[ac] (26.64)	74.62[ac] (26.41)	73.69[ac] (26.44)	74.79 (28.04)
	Engager	65.06[ab] (33.02)	65.99[ab] (33.66)	61.61[ab] (36.74)	64.87[a] (33.97)
Life is...	**Abstainer**	76.94[bc] (24.30)	78.38[bc] (23.91)	78.43[bc] (23.00)	74.44[c] (24.51)
	Experimenter	71.39[ac] (24.57)	72.41[ac] (24.38)	70.39[ac] (24.39)	76.66[c] (22.15)
	Engager	62.55[ab] (30.95)	63.51[ab] (31.55)	59.69[ab] (34.69)	64.02[ab] (32.96)

[a] Differs significantly from abstainers. [b] Differs significantly from experimenters. [c] Differs significantly from engagers. [d] All scores are on a 100 point scale. Some items were reverse scored so that on all variables a higher score represents a higher QoL. This table Reprinted from Journal of Adolescent Health Vol 29. Topolski, Patrick, Edwards, Huebner, Connell & Mount, Quality of life and Health Risk Behaviors among Adolescents, Page 432, Copyright (2001), with permission from Elsevier Science.

Without the covariates in the analysis, it was found that adolescents with disabilities reported lower QoL than adolescents without disabilities. However, self-rated health, depressive symptoms, and contextual variables

were significant covariates in the relationship between disability and QoL and including these variables in the model reduced the amount of variation so that there was no longer a mean difference between the groups on total YQOL-s perceptual scores. These findings suggested channels to improve the QoL of adolescents with disabilities, specifically, reducing social and environmental barriers to promote inclusion of adolescents with disabilities in school, family, and community activities. However, the exact causal nature of this relationship is unclear in the absence of longitudinal data.

THE YOUTH DISABILITY SCREENER (YDS)

Youth with disabilities are a group with special needs in maintaining health and function. One problem in identifying children and youth with disabilities is the lack of consensus on how to define the group. Definitions have typically been based on the presence of specific medical conditions. Recently, however, there has been a shift from definition by condition toward a broader definition of disability that encompasses health condition, function, activity, and participation. The model resulting for this broader defintion suggests that both environmental and personal factors play a role in disability.

The YDS is a 4-item disability screener based partly on the 1994 National Health Interview Survey on Disability (NHIS-D) (National Center for Health Statistics, 1994), and partly on the Questionnaire for Identifying Children with Chronic Conditions (QuICCC) (Stein, Westbrook, & Bauman, 1997), both of which are parent-reported. The QuICCC embodies the 'non-categorical' approach to disability identification in that is uses the consequences of conditions as a method of identifying children and youth with chronic conditions and is independent of diagnosis. The team ultimately decided upon the following definition of disability for the basis of the YDS:

> Disability is a limitation or inability to perform important life activities in a manner considered appropriate for the age and social role of the person because of a long-lasting physical, mental, or emotional condition.

The items comprising the YDS are contained in Appendix E. The YDS question regarding whether others would consider them to have a disability, was taken from the NHIS-D and has its origins in the social model of disability, which indicates that disability resides in the environment rather than the individual. Thus, we acknowledged that some individuals, whom others may consider to be person with a disability, do not consider themselves disabled.
The time qualification of 6 months was based on the work of Stein (1993).

Validation of the YDS

The YDS was fielded as part of the validation study of the YQOL-R. In this study it successfully identified 98% of adolescents with mobility disability, 62% of those diagnosed with ADHD, and 100% of those with a diagnosis of depression. It also identified 19% (n=18) of adolescents in the no condition group as having a disability. Among these adolescents, physicians for 17 of them indicated that they had some sort of chronic condition such as allergies, asthma, thyroid/hormone problem, and fatigue.

Using the YDS

The YDS also was fielded with the YQOL-S in a school based survey of 2,801 adolescents. In this study 21% of the students were identified as having some sort of disability. This proportion is comparable to the national figures from the 1994-1995 NHIS-D data (Newacheck et al., 1998).

Table 8 presents a breakdown by disability element for the adolescents who screened into the disability sample.

A complete description of how the YDS was used to assess QoL among adolescents with and without disabilities can be found in Edwards, Patrick, and Topolski (submitted) *Quality of Life of Adolescents with Disabilities*

Table 8
Frequency of Disability Elements - Junior and High School Sample

	Item N	Item %	Cumulative N	Cumulative %
Limited Activity	220	7.9 %	220	7.9
Physical Disability	277	9.9 %	365	13.0
Emotional Disability	269	9.6%	524	18.7
Other Disability	280	10.0 %	590	21.1

SCORING THE INSTRUMENTS

Scoring the YQOL-R

The YQOL-R produces a QoL profile for adolescents across four domains (Self, Relationships, Environment, and General QoL) in addition to a total QoL Score. Each item is taken to contribute equally to each subscale. Prior to the computation of the scales, items which are negatively worded are reverse coded so that a higher score represents a higher QoL. The scores are then transformed to a 0 to 100 point scale using the following formula:

$$tscore = \frac{actual\ raw\ score - lowest\ possible\ raw\ score}{possible\ raw\ score\ range} * 100$$

This transformation converts the lowest and highest possible scores to 0 and 100, respectively. Scores between these values represent the percentage of the total possible score achieved.

Subscales are formed by taking the mean of the items comprising the scale (as long as at least 80% of the items comprising the scale have been completed). If less than 80% of the items have responses, a missing value is assigned to the scale. *The scoring algorithm, written in SPSS syntax, is included on the enclosed disk and is presented in Appendix F.*

The total score is derived by taking the mean of the four domains. All domain scores must be nonmissing or else the total score is set to missing. The items of the YQOL-R are presented in Appendix B. The items comprising each domain scale and the total score are presented in Table 9 below. Depression has been shown to have a negative

impact on YQOL-R and YQOL-S scores. Therefore, it is recommended that analyses aimed at assessing group differences in QoL be freed from their association with depression by using a measure of depressive symptomatology such as the Children's Depression Inventory (CDI, Kovacs, 1992) as a covariate in the analysis.

Table 9
Items by Perceptual Domain

	Items comprising domain
Self Domain	1 - 12, 21r* and 28r*
Relationship Domain	13 - 20, 22 - 27
Environmental Domain	29 - 38
General QoL Domain	39 - 41
Total Perceptual Score	1 - 41

*r denotes that the item is reverse scored. (See Appendix B for items)

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Scoring the YQOL-S

Like the YQOL-R the all items are first transposed to t-scores on a 100-point scale (see formula above). The YQOL-S perceptual items can be used individually or a total score can be calculated. Item number 3 of the YQOL-S (I feel alone in my life) is reverse scored prior to calculating a total score. The mean of the first 7 transformed perceptual items is then calculated to form the total YQOL-S perceptual score. At least 6 of the 7 items must have responses in order to compute at total score. Otherwise, the total score is set to a missing value. Item number 8 (Compared with others my age, I feel my life is...) is not included in the total score calculation because its anchor scheme is different from those of the other items and thus not directly comparable. The YQOL-S perceptual items are presented in Appendix D and the SPSS syntax for reverse scoring item 3 and computing the total perceptual score is presented in Appendix G.

Scoring Contextual Items

As with the perceptual items the contextual items, presented in Appendix C, are first transformed into t-scores on a 100-point scale (see formula above) and negative items are reverse scored so that a higher score indicates a higher QoL. The items that are reverse scored are presented in Table 10 below.

The contextual items are used as individual indicators. These items are potentially verifiable, and may be used to assess specific areas in which adolescents are thought to differ from their peers (e.g., adolescents with disabilities sometimes miss out on activities they want to do more often than their peers without disabilities). They may also be used as covariates to tentatively assess the potential usefulness of a particular intervention. That is, if we want to consider whether an intervention aimed at helping adolescents with disabilities to become more integrated in social activities at school might help improve their QoL, then we could control for "made to feel

unwelcome because of how you look" and assess whether the scores between adolescent with and without disabilities become more similar.

Table 10
Contextual Items Reverse Scored

Contextual Item Number	Variable Label
4	Behavior caused problems
6	Serious emotional mental health problems
7	Couldn't shake the blues
8	Family had serious arguments
9	Missed out on an activity
10	Felt unwelcome because of looks

Scoring the YDS

The YDS is used to determine whether an adolescent has a self-reported disability. The four items of the YDS are answered as either "yes" or "no". Adolescents who endorse any one of the 4 items as a "yes" are considered to have a self-reported disability.

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APPENDIX A

YQOL-R PERCEPTUAL ITEMS BY DOMAIN

Self
1.[a] I keep trying, even if at first I don't succeed
2. I can handle most difficulties that come my way
3. I am able to do most things as well as I want
4. I feel good about myself
5. I feel I am important to others
6. I feel comfortable with my sexual feelings and behaviors
7. I have enough energy to do the things I want to do
8. I am pleased with how I look
9. I feel comfortable with the amount of stress in my life
10. I feel it is okay if I make mistakes
11. I feel my life has meaning
12. My personal beliefs give me strength
21. I feel alone in my life
28. I feel left out because of who I am
Relationships
13. I feel most adults treat me fairly
14. I feel I am getting the right amount of attention from my family
15. I feel understood by my parents or guardians
16. I feel useful and important to my family
17. I feel my family cares about me
18. My family encourages me to do my best
19. I feel I am getting along with my parents or guardians
20. I feel my parents or guardians allow me to participate in important decisions which affect me
22. I try to be a role model for others

Relationships (continued)
23. I can tell my friends how I really feel
24. I am happy with the friends I have
25. I am satisfied with my social life
26. I feel I can take part in the same activities as others my age
27. People my age treat me with respect
Environment
29. I feel my life is full of interesting things to do
30. I like trying new things
31. I like my neighborhood
32. I look forward to the future
33. My family has enough money to live a good life
34. I feel safe when I am at home
35. I feel I am getting a good education
36. I know how to get the information that I need
37. I enjoy learning new things
38. I feel safe when I am at school
General QoL
39. I enjoy life
40. I am satisfied with the way my life is now
41. I feel life is worthwhile

Note. Items 2-4, 6-8, 9-11, 13, 14, 15, 19, 20, 23, 25, 26, 27, 33-36, 38, 40, 41 use a 11-point rating scale with adjectival anchors "Not at All" to "Completely". Items 1, 5, 12, 16-18, 21, 22, 24, 28-32, 37, 39 use a 11-point rating scale with adjectival anchors "Not at All" to "A Great Deal". Items 21 and 28 must be reverse scored prior to computing scales.

[a]Items numbered as they appear in the YQOL-R.

Appendix B: YQOL-R Perceptual Instrument

Evaluating Your Life

Following are some statements that you might make about yourself. Please circle the number on the scale that best describes how closely the statement applies to you IN GENERAL. There are no right or wrong answers, we are only interested in how you feel about your life.

1. I keep trying, even if at first I don't succeed *(please circle the number)*

NOT AT ALL	0	1	2	3	4	5	6	7	8	9	10	A GREAT DEAL

2. I can handle most difficulties that come my way *(please circle the number)*

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

3. I am able to do most things as well as I want *(please circle the number)*

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

4. I feel good about myself *(please circle the number)*

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

5. I feel I am important to others *(please circle the number)*

NOT AT ALL	0	1	2	3	4	5	6	7	8	9	10	A GREAT DEAL

6. I feel comfortable with my sexual feelings and behaviors *(please circle the number)*

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

7. I have enough energy to do the things I want to do *(please circle the number)*

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

8. I am pleased with how I look *(please circle the number)*

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

9. I feel comfortable with the amount of stress in my life *(please circle the number)*

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

10. I feel it is okay if I make mistakes *(please circle the number)*

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

11. I feel my life has meaning *(please circle the number)*

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

12. My personal beliefs give me strength *(please circle the number)*

NOT AT ALL	0	1	2	3	4	5	6	7	8	9	10	A GREAT DEAL

13. I feel adults treat me fairly *(please circle the number)*

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

14. I feel I am getting the right amount of attention from my family *(please circle the number)*

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

15. I feel understood by my parents or guardians *(please circle the number)*

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

16. I feel useful and important to my family *(please circle the number)*

NOT AT ALL	0	1	2	3	4	5	6	7	8	9	10	A GREAT DEAL

17. I feel my family cares about me *(please circle the number)*

NOT AT ALL	0	1	2	3	4	5	6	7	8	9	10	A GREAT DEAL

18. My family encourages me to do my best *(please circle the number)*

NOT AT ALL	0	1	2	3	4	5	6	7	8	9	10	A GREAT DEAL

19. I feel I am getting along with my parents or guardians *(please circle the number)*

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

20. I feel my parents or guardians allow me to participate in important decisions which affect me *(please circle the number)*

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

21. I feel alone in my life *(please circle the number)*

NOT AT ALL	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	A GREAT DEAL

22. I try to be a role model for others *(please circle the number)*

NOT AT ALL	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	A GREAT DEAL

23. I can tell my friends how I really feel *(please circle the number)*

NOT AT ALL	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	COMPLETELY

24. I am happy with the friends I have *(please circle the number)*

NOT AT ALL	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	COMPLETELY

25. I am satisfied with my social life *(please circle the number)*

NOT AT ALL	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	COMPLETELY

26. I feel I can take part in the same activities as others my age *(please circle the number)*

NOT AT ALL	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	COMPLETELY

27. People my age treat me with respect *(please circle the number)*

NOT AT ALL	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	COMPLETELY

28. I feel left out because of who I am *(please circle the number)*

NOT AT ALL	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	A GREAT DEAL

29. I feel my life is full of interesting things to do *(please circle the number)*

NOT AT ALL	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	A GREAT DEAL

30. I like trying new things *(please circle the number)*

NOT AT ALL	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	A GREAT DEAL

31. I like my neighborhood *(please circle the number)*

NOT AT ALL	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	A GREAT DEAL

32. I look forward to the future *(please circle the number)*

NOT AT ALL	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	A GREAT DEAL

33. My family has enough money to live a good life *(please circle the number)*

NOT AT ALL	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	COMPLETELY

34. I feel safe when I am at home *(please circle the number)*

NOT AT ALL	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	COMPLETELY

35. I feel I am getting a good education *(please circle the number)*

NOT AT ALL	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	COMPLETELY

36. I know how to get the information that I need *(please circle the number)*

NOT AT ALL	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	COMPLETELY

37. I enjoy learning new things *(please circle the number)*

NOT AT ALL	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	A GREAT DEAL

38. I feel safe when I am at school *(please circle the number)*

NOT AT ALL	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	COMPLETELY

39. I enjoy life *(please circle the number)*

NOT AT ALL	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	A GREAT DEAL

40. I am satisfied with the way my life is now *(please circle the number)*

NOT AT ALL	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	COMPLETELY

41. I feel life is worthwhile *(please circle the number)*

NOT AT ALL	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	COMPLETELY

APPENDIX C: YQOL-R Contextual Items

Describing Your Life

Following are some statements that you might make about yourself. Please circle the answer that best describes how closely the statement applies to you. There are no right or wrong answers, we are only interested in how you feel about your life.

1.	During the past month, how often did you have a conversation with an adult about something that is important to you? *(please circle your answer)*	NEVER	ALMOST NEVER	SOMETIMES	FAIRLY OFTEN	VERY OFTEN
2.	During the past month, how often did you help someone who needed it? *(please circle your answer)*	NEVER	ALMOST NEVER	SOMETIMES	FAIRLY OFTEN	VERY OFTEN
3.	During the past month, how often have your parents or guardians let you make your own decisions about what time you go to bed? *(please circle your answer)*	NEVER	ALMOST NEVER	SOMETIMES	FAIRLY OFTEN	VERY OFTEN
4.	During the past month, how often has your behavior caused problems with your family? *(please circle your answer)*	NEVER	ALMOST NEVER	SOMETIMES	FAIRLY OFTEN	VERY OFTEN
5.	During the past month, how often did you spend time with a friend having a good time outside of school? *(please circle your answer)*	NEVER	ALMOST NEVER	SOMETIMES	FAIRLY OFTEN	VERY OFTEN
6.	During the past month, how often have you had serious emotional or mental health problems that you felt you needed help with? *(please circle your answer)*	NEVER	ALMOST NEVER	SOMETIMES	FAIRLY OFTEN	VERY OFTEN
7.	During the past month, how often did you feel that you could not shake off the blues, even with help from your family & friends? *(please circle your answer)*	NEVER	ALMOST NEVER	SOMETIMES	FAIRLY OFTEN	VERY OFTEN
8.	During the past month, how often have any of your family members had serious arguments with one another? *(please circle your answer)*	NEVER	ALMOST NEVER	SOMETIMES	FAIRLY OFTEN	VERY OFTEN
9.	During the past month, how often did you miss out on an activity that you wanted to do because of any physical or emotional problems you have? *(please circle your answer)*	NEVER	ALMOST NEVER	SOMETIMES	FAIRLY OFTEN	VERY OFTEN

10. During the past month, how often have people your age made you feel unwelcome because of how you look? *(please circle your answer)*	NEVER	ALMOST NEVER	SOMETIMES	FAIRLY OFTEN	VERY OFTEN
11. During the past month, how often have you been in a good mood? *(please circle your answer)*	NEVER	ALMOST NEVER	SOMETIMES	FAIRLY OFTEN	VERY OFTEN
12. During the past month, how often have you had enough food and a safe place to live? *(please circle your answer)*	NEVER	ALMOST NEVER	SOMETIMES	FAIRLY OFTEN	VERY OFTEN

13. During the past week, how many days did you work around the house, such as cleaning, cooking, laundry, yard work, or caring for a pet? *(please circle your answer)*	0 DAYS	1 DAY	2 DAYS	3 DAYS	4 OR MORE DAYS
14. During the past week, how many days did you have dinner with a parent, guardian, or other adult in your family? *(please circle your answer)*	0 DAYS	1 DAY	2 DAYS	3 DAYS	4 OR MORE DAYS
15. During the past week, how many days were you at home WITHOUT an adult for AT LEAST THREE HOURS? *(please circle your answer)*	0 DAYS	1 DAY	2 DAYS	3 DAYS	4 OR MORE DAYS

APPENDIX D: YQOL-S Perceptual Items

Evaluating Your Life

Following are some statements that you might make about yourself. Please circle the number on the scale that best describes how closely the statement applies to you. There are no right or wrong answers, we are only interested in how you feel about your life.

1. I feel I am getting along with my parents or guardians *(please circle the number)*

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

2. I look forward to the future *(please circle the number)*

NOT AT ALL	0	1	2	3	4	5	6	7	8	9	10	A GREAT DEAL

3. I feel alone in my life *(please circle the number)*

NOT AT ALL	0	1	2	3	4	5	6	7	8	9	10	A GREAT DEAL

4. I feel good about myself *(please circle the number)*

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

5. I enjoy life *(please circle the number)*

NOT AT ALL	0	1	2	3	4	5	6	7	8	9	10	A GREAT DEAL

6. I am satisfied with the way my life is now *(please circle the number)*

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

7. I feel life is worthwhile *(please circle the number)*

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

8. Compared with others my age, I feel my life is… *(please circle the number)*

MUCH WORSE THAN OTHERS	0	1	2	3	4	5	6	7	8	9	10	MUCH BETTER THAN OTHERS

*Add any of the 15 contextual items from the YQOL-R to field with this version

APPENDIX E: YDS Items

Your Health and Disabilities

Following are some questions about your health and any disabilities that you might have. Please circle the answer that best describes how closely the statement applies to you. NOTE: "LONG-TERM" REFERS TO DIFFICULTIES THAT HAVE LASTED OR ARE EXPECTED TO LAST **6 MONTHS OR MORE**.

1. Do you have any physical disabilities or long-term health problems? *(please circle your answer)*	NO	YES	I DON'T KNOW
2. Do you have any long-term emotional problems or learning disabilities? *(please circle your answer)*	NO	YES	I DON'T KNOW
3. Would other people consider you to have ANY disabilities or long-term health problems, including physical health, emotional, or learning problems? *(please circle your answer)*	NO	YES	I DON'T KNOW
4. Are you limited in any activities because of ANY disabilities or long-term health problems, including physical health, emotional, or learning problems? *(please circle your answer)*	NO	YES	I DON'T KNOW

APPENDIX F: SPSS Syntax for Computing YQOL-R Perceptual Scores

```
*First Step - Recode variables.
RECODE self21 (0=10)  (1=9)  (2=8)  (3=7)  (4=6)  (5=5)  (6=4)  (7=3)  (8=2)  (9=1) (10=0)
(SYSMIS=SYSMIS)  INTO  self21r .

RECODE Self28 (0=10) (1=9) (2=8) (3=7) (4=6) (5=5) (6=4) (7=3) (8=2) (9=1) (10=0)
(sysmis=sysmis) INTO Self28r.
EXECUTE.

*Second Step - Compute Transformed Scores.
COMPUTE Self1t = ((Self1-0)/10)*100.
COMPUTE Self2t = ((Self2-0)/10)*100.
COMPUTE Self3t = ((Self3-0)/10)*100.
COMPUTE Self4t = ((Self4-0)/10)*100.
COMPUTE Self5t = ((Self5-0)/10)*100.
COMPUTE Self6t  =((Self6-0)/10)*100.
COMPUTE Self7t = ((Self7-0)/10)*100.
COMPUTE Self8t  = ((Self8-0)/10)*100.
COMPUTE Self9t  = ((Self9-0)/10)*100.
COMPUTE Self10t = ((Self10-0)/10)*100.
COMPUTE Self11t = ((Self11-0)/10)*100.
COMPUTE Self12t = ((Self12-0)/10)*100.
COMPUTE Self21rt =((Self21r-0)/10)*100.
COMPUTE Self28rt =((Self28r-0)/10)*100.
COMPUTE Rel13t = ((Rel13-0)/10)*100.
COMPUTE Rel14t = ((Rel14-0)/10)*100.
COMPUTE Rel15t = ((Rel15-0)/10)*100.
COMPUTE Rel16t = ((Rel16-0)/10)*100.
COMPUTE Rel17t = ((Rel17-0)/10)*100.
COMPUTE Rel18t = ((Rel18-0)/10)*100.
COMPUTE Rel19t = ((Rel19-0)/10)*100.
COMPUTE Rel20t = ((Rel20-0)/10)*100.
COMPUTE Rel22t = ((Rel22-0)/10)*100.
COMPUTE Rel23t = ((Rel23-0)/10)*100.
COMPUTE Rel24t = ((Rel24-0)/10)*100.
COMPUTE Rel25t = ((Rel25-0)/10)*100.
COMPUTE Rel26t = ((Rel26-0)/10)*100.
COMPUTE Rel27t = ((Rel27-0)/10)*100.
COMPUTE Env29t = ((Env29-0)/10)*100.
COMPUTE Env30t = ((Env30-0)/10)*100.
COMPUTE Env31t = ((Env31-0)/10)*100.
COMPUTE Env32t = ((Env32-0)/10)*100.
COMPUTE Env33t = ((Env33-0)/10)*100.
COMPUTE Env34t = ((Env34-0)/10)*100.
COMPUTE Env35t = ((Env35-0)/10)*100.
COMPUTE Env36t = ((Env36-0)/10)*100.
COMPUTE Env37t = ((Env37-0)/10)*100.
COMPUTE Env38t = ((Env38-0)/10)*100.
COMPUTE Gen39t = ((Gen39-0)/10)*100.
COMPUTE Gen40t = ((Gen40-0)/10)*100.
COMPUTE Gen41t = ((Gen41-0)/10)*100.
EXECUTE .
```

```
*Third Step - Adding variable labels and value labels.
VARIABLE LABELS
 Self1t 'keep trying'
 Self2t 'handle difficulties'
 Self3t 'able to do things well'
 Self4t 'good about self'
 Self5t 'important to others'
 Self6t 'comfortable with sexual feelings'
 Self7t 'enough energy'
 Self8t 'pleased with looks'
 Self9t 'comfortable with stress'
 Self10t 'okay to make mistakes'
 Self11t 'life has meaning'
 Self12t 'beliefs give strength'
 Self21rt 'alone in life'
 Self28rt 'left out '
 Rel13t 'adults treat me fairly'
 Rel14t 'attention from family'
 Rel15t 'understood by parents'
 Rel16t 'useful to family'
 Rel17t 'family cares'
 Rel18t 'family encourages'
 Rel19t 'get along with parents'
 Rel20t 'participate in decisions'
 Rel22t 'role model'
 Rel23t 'tell friends feelings'
 Rel24t 'happy with friends'
 Rel25t 'satisfied with social life'
 Rel26t 'take part in activities'
 Rel27t 'respect from peers'
 Env29t ' life interesting'
 Env30t 'try new things'
 Env31t 'like neighborhood'
 Env32t 'forward to future'
 Env33t 'enough money'
 Env34t 'safe at home'
 Env35t 'good education'
 Env36t 'get information'
 Env37t 'enjoy learning'
 Env38t 'safe at school'
 Gen39t 'enjoy life'
 Gen40t 'satisfied with life'
 Gen41t 'life is worthwhile'.

* Fourth Step - Computing and Labeling Domain and Total Scores.
COMPUTE GenQol=mean.3(Gen39t,Gen40t, Gen41t).
COMPUTE SelfDom=mean.12(Self1t,Self2t,Self3t,Self4t,Self5t,Self6t,Self7t,Self8t,Self9t,Self10t,
    Self11t,Self12t,Self21rt,Self28rt).
COMPUTE
RelDom=mean.12(Rel13t,Rel14t,Rel15t,Rel16t,Rel17t,Rel18t,Rel19t,Rel20t,Rel22t,Rel23t,Rel24,
   Rel25t,Rel26t,Rel27t).
COMPUTE
EnvDom=mean.8(Env29t,Env30t,Env31t,Env32t,Env33t,Env34t,Env35t,Env36t,Env37t,Env38t).
COMPUTE TotQoL=mean.4(Genqol,SelfDom,RelDom,EnvDom).
```

```
EXECUTE.

VARIABLE LABELS
    GenQol 'General Quality of Life Domain Score'
    SelfDom 'Self Domain Score'
    RelDom  'Relationships Domain Score'
    EnvDom 'Environment Domain Score'
    TotQol    'Total Quality of Life Score'.
```

APPENDIX G: SPSS Syntax for Scoring the YQOL-S

If you will be using both the YQOL-R and YQOL-S it is best to use the same variable names for scoring both instruments. The code below reflects the variable names from Appendix A, with the variables listed in the order of the YQOL-S Perceptual items.

```
*First Step - Recode variables.
RECODE self21 (0=10)  (1=9)  (2=8)  (3=7)  (4=6)  (5=5)  (6=4)  (7=3)  (8=2)  (9=1) (10=0)
(SYSMIS=SYSMIS)  INTO  self21r .
EXECUTE.


*Second Step – Computing the transformed scores.
COMPUTE Rel19t = ((Rel19-0)/10)*100.
COMPUTE Env32t = ((Env32-0)/10)*100 .
COMPUTE Self21rt =((Self21r-0)/10)*100 .
COMPUTE Self4t = ((Self4-0)/10)*100 .
COMPUTE Gen39t = ((Gen39-0)/10)*100 .
COMPUTE Gen40t = ((Gen40-0)/10)*100 .
COMPUTE Gen41t = ((Gen41-0)/10)*100 .
COMPUTE Com8T = ((Com8-0)/10)*100.
EXECUTE.


*Third Step - Adding variable labels.
VARIABLE LABELS
Self4t 'good about self'
Self21rt 'alone in life'
Rel19t 'get along with parents'
Env32t 'forward to future'
Gen39t 'enjoy life'
Gen40t 'satisfied with life'
Gen41t 'life is worthwhile'
Com8t ‘compared to others my life is…’.

*Forth Step – Computing total Score.
Compute TotQOL=mean.6(self4t,self21rt,rel19t,env32t,gen39t,gen40t,gen41t).
EXECUTE.

*Fifth Step – Labeling the Total YQOL-S Perceptual Score.
VARIABLE LABEL
TotQOL ‘Total YQOL-S Perceptual Score’.
```

Appendix H
Format for Sending Data Files to SeaQoL Group

The data may be sent to the SeaQoL group using any of the following programs: Ms Access, Excel, SPSS, SAS or as an tab-delimited ASCII or .rft file. The variables should be in the order of the YQOL-R (or YQOL-S) with labels as below. In addition to the YQOL variables, demographic data on each participant should be included. The demographic variables must include: age, gender, ethnicity; and if available, height and weight. The data file should also contain information as to what study group each participant was in and a cover sheet explaining the purpose of the project and how study groups were defined and identified.

Self1t 'keep trying'
Self2t 'handle difficulties'
Self3t 'able to do things well'
Self4t 'good about self'
Self5t 'important to others'
Self6t 'comfortable with sexual feelings'
Self7t 'enough energy'
Self8t 'pleased with looks'
Self9t 'comfortable with stress'
Self10t 'okay to make mistakes'
Self11t 'life has meaning'
Self12t 'beliefs give strength'
Rel13t 'adults treat me fairly'
Rel14t 'attention from family'
Rel15t 'understood by parents'
Rel16t 'useful to family'
Rel17t 'family cares'
Rel18t 'family encourages'
Rel19t 'get along with parents'
Rel20t 'participate in decisions'
Self21rt 'alone in life'
Rel22t 'role model'
Rel23t 'tell friends feelings'
Rel24t 'happy with friends'
Rel25t 'satisfied with social life'
Rel26t 'take part in activities'
Rel27t 'respect from peers'
Self28rt 'left out '
Env29t ' life interesting'
Env30t 'try new things'
Env31t 'like neighborhood'
Env32t 'forward to future'
Env33t 'enough money'
Env34t 'safe at home'
Env35t 'good education'
Env36t 'get information'
Env37t 'enjoy learning'
Env38t 'safe at school'
Gen39t 'enjoy life'
Gen40t 'satisfied with life'
Gen41t 'life is worthwhile'.

Age ‘age of participant’.
Gender ‘sex of participant’
Ethnic ‘ethnicity of participant’.
Height ‘height of participant’.
Weight ‘weight of participant’.
Group ‘study group for participant’.