

AD _____

Award Number: DAMD17-02-1-0654

TITLE: Health-Related Quality of Life for Pediatric NF-1 Patients

PRINCIPAL INVESTIGATOR: Andrew S. Bradlyn, Ph.D.

CONTRACTING ORGANIZATION: West Virginia University Research Corporation
Morgantown, WV 26506

REPORT DATE: August 2007

TYPE OF REPORT: Final

PREPARED FOR: U.S. Army Medical Research and Materiel Command
Fort Detrick, Maryland 21702-5012

DISTRIBUTION STATEMENT: Approved for Public Release;
Distribution Unlimited

The views, opinions and/or findings contained in this report are those of the author(s) and should not be construed as an official Department of the Army position, policy or decision unless so designated by other documentation.

REPORT DOCUMENTATION PAGE				Form Approved OMB No. 0704-0188	
Public reporting burden for this collection of information is estimated to average 1 hour per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing this collection of information. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to Department of Defense, Washington Headquarters Services, Directorate for Information Operations and Reports (0704-0188), 1215 Jefferson Davis Highway, Suite 1204, Arlington, VA 22202-4302. Respondents should be aware that notwithstanding any other provision of law, no person shall be subject to any penalty for failing to comply with a collection of information if it does not display a currently valid OMB control number. PLEASE DO NOT RETURN YOUR FORM TO THE ABOVE ADDRESS.					
1. REPORT DATE 30-08-2007		2. REPORT TYPE Final		3. DATES COVERED 1 AUG 2002 - 30 JUL 2007	
4. TITLE AND SUBTITLE Health-Related Quality of Life for Pediatric NF-1 Patients				5a. CONTRACT NUMBER	
				5b. GRANT NUMBER DAMD17-02-1-0654	
				5c. PROGRAM ELEMENT NUMBER	
6. AUTHOR(S) Andrew S. Bradlyn, Ph.D. Email: abradlyn@hsc.wvu.edu				5d. PROJECT NUMBER	
				5e. TASK NUMBER	
				5f. WORK UNIT NUMBER	
7. PERFORMING ORGANIZATION NAME(S) AND ADDRESS(ES) West Virginia University Research Corporation Morgantown, WV 26506				8. PERFORMING ORGANIZATION REPORT NUMBER	
9. SPONSORING / MONITORING AGENCY NAME(S) AND ADDRESS(ES) U.S. Army Medical Research and Materiel Command Fort Detrick, Maryland 21702-5012				10. SPONSOR/MONITOR'S ACRONYM(S)	
				11. SPONSOR/MONITOR'S REPORT NUMBER(S)	
12. DISTRIBUTION / AVAILABILITY STATEMENT Approved for Public Release; Distribution Unlimited					
13. SUPPLEMENTARY NOTES					
14. ABSTRACT The objective of this project is to develop an NF1-specific health-related quality of life (HRQL) instrument for use with pediatric patients. Semi-structured interviews with children with NF1, their parents, and teachers were used to derive important domains and item content, and the first-generation instrument was developed. This instrument underwent an initial examination of its psychometric properties and the content was revised accordingly. Following the initial field trial, the second generation instrument was administered in a battery of measures to further assess its reliability and validity. During this project, we completed and transcribed interviews with children, parents, healthcare providers and teachers to identify key item content. This content review was then used to develop the first-generation instrument, which was completed by a sample of children with NF1 and their parents and the responses analyzed for internal consistency and feasibility. The revised version of the instrument was administered to a different sample of children with NF1 and their parents; the sample also completed a variety of standardized self- and parent-report measures of behavior and generic health-related quality of life. Analyses focused on the test-retest reliability and validity of the instrument. The NF1-specific instrument demonstrated acceptable internal consistency and test-retest reliability over a 4-week interval. Subscales of the NF1 instrument correlated significantly, and in the expected direction with previously standardized measures of similar constructs, supporting the overall validity of the instrument. However, the subscales did not demonstrate specificity in the construct being assessed and may be reflecting a more general level of functioning or distress. The instrument was not rated as either difficult or burdensome to complete by child or parent informants.					
15. SUBJECT TERMS Quality of Life.					
16. SECURITY CLASSIFICATION OF:			17. LIMITATION OF ABSTRACT	18. NUMBER OF PAGES	19a. NAME OF RESPONSIBLE PERSON
a. REPORT	b. ABSTRACT	c. THIS PAGE			USAMRMC
U	U	U	UU	66	19b. TELEPHONE NUMBER (include area code)

Table of Contents

Introduction.....	5
Body.....	5
Key Research Accomplishments.....	19
Reportable Outcomes.....	20
Conclusions.....	20
References.....	20
Tables.....	22
Appendices.....	45

Health-Related Quality of Life for Pediatric NF-1 Patients

Andrew S. Bradlyn, Ph.D. (Principal Investigator)

1. INTRODUCTION

The objective of this project was to develop an NF1-specific health-related quality of life (HRQL) instrument for pediatric patients and their parents. Semi-structured interviews with children with NF1, their parents, and teachers yielded relevant domains and content that were used to develop the first-generation instrument. This first-generation instrument was field tested for psychometric properties and understandability and then revised. The revised instrument was completed by a group of children and their parents to test its psychometric properties (validity and reliability). It is our hypothesis that the addition of this disease-specific measure will significantly improve the descriptiveness and quantification of the impact of NF1 and its treatment on children's lives.

2. BODY

The original Statement of Work identified the following tasks:

Task 1: Identify domains and items to reflect important aspects of HRQL (COMPLETED)

- Complete review of literature to gather previously identified HRQL topics
- Develop standardized interviews for patients, parents, teachers, and health care professionals
- Pilot interviews and modify as needed
- Conduct interviews of patients, parents, teachers and health care professionals
- Transcribe interviews, review for functioning areas impacted by NF1.

Task 2: Administer preliminary items to sample of NF1 patients and parents and use item analysis methods to construct preliminary HRQL instrument (COMPLETED)

- Recruit NF1 participants and parents
- Mail out questionnaires for completion and return
- Enter and analyze data
- Produce final NF1-specific instrument for studies in subsequent tasks

Task 3: Conduct reliability, validity and responsivity studies for NF1 instrument (COMPLETED)

- Recruit NF1 participants and parents
- Mail out initial set of questionnaires for completion and return
- Mail out followup set of questionnaires for completion and return
- Analyze data to describe the psychometric properties of the NF1-specific instrument ("NFqol")

Additionally, although not stated in the original Statement of Work, we were required to gain approval from both the Army/Department of Defense Human Subjects Review Board and our local Institutional Review Board prior to recruiting participants. Because of the manner in which the projects were proposed, and the reliance on material/questionnaires developed at each stage, it was necessary to submit separate Human Subjects protocols for each of the 3 projects (interviews, first-generation validation, and final version validation).

Status of Work. As noted in prior reports Task 1 and Task 2 have been completed, and are summarized below. Task 3 was completed during this interval and that work is also summarized below.

Task 1: Identify domains and items to reflect important aspects of HRQL

- *Complete review of the literature to gather previously-identified HRQL-related topics.* As we noted in our proposal, there have been no prior instruments that specifically assess HRQL for NF1 patients. There are however, several dermatological measures (e.g., SkinDex) that were identified and reviewed for content. Prior literature regarding psychological and psychosocial functioning was reviewed and findings were noted. This information was used to develop the interviews used to gather content information.
- *Develop standardized interviews for participants.* This task was completed in Year 1, however the interview guide for the child participants was modified to be more “child friendly” as suggested in the Year 1 review.
- *Pilot interviews and modify as needed.* Prior to being used with participants, the interviews were piloted and revised to reflect the feedback received regarding length, complexity, and clarity.
- *Conduct interviews.* We recruited participants through web sites (e.g., Neurofibromatosis Foundation; Neurofibromatosis, Inc), web bulletin boards, mailings and contacts with NF clinics and state associations, and presentations. The following table provides descriptive information about the participants:

Variable	Description
Parent Participants	<u>N</u> =25
Gender	3 male; 22 female
Age of Child	<u>M</u> = 13.1 years
Severity of Child (Riccardi)	Range = 1 – 4 Mode = 1
Child Participants (ages 8-17)	<u>N</u> = 20
Age	<u>M</u> = 12.34 <u>sd</u> = 2.6
Gender	Range = 8 – 16 8 male 12 female
Severity (Riccardi)	Range = 1 – 4 Mode = 1
Teacher Participants	<u>N</u> = 2

- *Transcribe interviews and review for functioning areas impacted by NF-1.*
Interviews were continued to the point of redundancy (i.e., no new information elicited). All interviews were transcribed and reviewed and items were written to reflect the domains and issues that were derived from the interviews and from the existing literature.

Results and Discussion of Research Activities from Task 1. The primary findings relate to the specific themes and issues identified by participants. Children, youth and parents responded to a broad range of interview questions, designed to elicit information regarding physical, social, and emotional functioning (the three core areas of health as defined by the World Health Organization). Interviews with teachers covered a similar breadth of topics, but the questions emphasized the child's functioning in the school setting. The following themes and specific issues were identified from interviews with children, youth and families (checkmarks indicate that at least one participant in that specific group reported difficulties):

Theme	Parents	Children (8-12)	Youth (13-17)	Teachers	Comments Examples
Understanding NF1	✓	✓			Frustration with having NF1, difficulty understanding the disease
Problems with sleep	✓	✓	✓		Difficulties falling asleep, maintaining sleep, or early morning awakening
Problems with appetite	✓	✓			
Problems with sensation	✓	✓	✓	✓	Sight, hearing, touch,
Pain	✓	✓	✓		Related to tumors, surgeries, nerve involvement
Specific physical symptoms	✓	✓	✓	✓	NF1-specific symptoms; other miscellaneous
Specific psychological or behavioral symptoms	✓	✓	✓	✓	Symptoms related to Attention Deficit Hyperactivity Disorder, Pervasive Developmental Disorders, Mood Disorders, Anxiety Disorders
Specific learning/cognitive problems and/or classroom difficulties	✓	✓	✓	✓	Reading, writing, attendance, learning disability, classroom modifications
Social concerns	✓	✓	✓	✓	Difficulties with family members

					and/or friends; preferring solitary activities; teasing
Fine and/or gross motor coordination	✓	✓	✓	✓	Handwriting, running, walking, clumsiness
Concerns about physical appearance	✓	✓	✓		Café-au-lait spots, stature, over/underweight, head size
Difficulties with speech and language	✓	✓	✓	✓	Articulation problems

- In terms of physical impairments, several issues were commonly identified. In particular, several participants reported significant concerns regarding ongoing, chronic pain and acute recurrent pains (e.g., headache). Parents, children and teachers commonly noted motor problems, such as poor fine and gross motor coordination; these were evidenced by clumsiness and handwriting problems, for example. A number of children and parents reported difficulties with sleep (either initiating or maintaining sleep), and sensory difficulties (auditory or visual) were frequently endorsed. As noted below, although over- or hyper-activity was reported (often associated with the diagnosis of Attention Deficit Hyperactivity Disorder), several participants noted easy fatigability, to the point of being an impediment to participation in day-to-day activities. Finally, participants noted a wide range of stature and weight concerns, ranging including short-stature and both over- and under-weight status, which was often attributed to NF1.
- Psychological impairments reported included a number of diagnosed psychiatric disorders, including Attention Deficit Hyperactivity Disorder, Mood Disorders (e.g., Major Depressive Disorder, Bipolar Affective Disorder), Pervasive Developmental Disorders, and Anxiety Disorders (e.g., Panic Disorder). Participants were often unclear as to whether these were related to NF1; however, they did note impairments in school and social relations, in particular that were related to these disorders.
- Participants reported social impairments, as well. These often included situations in which individuals were teased by peers regarding their physical appearance. Additionally, a number of participants noted a preference for solitary activities, as compared to group socialization. It is important to note however, that a substantial number of children and youth described themselves as very outgoing and engaging socially, and that they perceived their peers and family as being supportive.
- In their consensus statement, the NF1 Cognitive Disorders Task Force (North et al., 1997a) concluded that there was a high incidence of learning disabilities (30-65%) in individuals with NF, as compared to the general population. Our data are consistent with this finding as well, as a number of participants (children, youth, parents and teachers) noted a range of cognitive difficulties that were often associated with impaired school performance. We frequently noted children and youth who received special education services as well, whether it

was in the form of full-time self-contained classes or domain-specific assistance (e.g., reading or mathematics support).

- In terms of behavioral difficulties, the themes and issues identified by our participants were generally consistent with the pattern that has emerged in the scientific literature. For example, Wadsby et al (1989) reported that children with NF were more likely than their siblings to have difficulties with sleeping, disruptive behaviors, and distractibility. Although not conclusive, there are data to suggest a high incidence of ADHD in children with NF (cf., Moore et al., 1996; North et al., 1997b) and participants in our interviews frequently reported either a formal diagnosis of ADHD or symptoms consistent with this diagnosis. Reporting on an investigation comparing NF1 individuals with non-affected siblings and parents, Koth et al., (2000) concluded that ADHD may occur as a component of NF1.
- Although the findings were limited by a relatively small sample size, Spaepen, Borghgraef, and Fryns (1992) found that approximately 50% of their sample had parent-reported behavior problems that were at a level similar to children referred for psychiatric treatment. Problems reported in this sample included social withdrawal, aggressiveness, anxiety, and somatic complaints.
- The physical symptoms reported by our participants were generally consistent with what might be predicted for individuals with NF1 and a host of co-morbid conditions. Headaches, short stature, macrocephaly and seizures are frequently noted manifestations of the disease (cf., Goldberg et al., 1996), and were reported as concerns by parents, youth and children.
- Overall, the information gathered from the interviews was generally consistent with published data regarding the effects of NF1 on individuals. The interviews do provide a context for understanding the impact of the disease however, and in particular highlight the spectrum of effects (from minimal to significant impairment) that may be experienced with this disease. Anecdotally, we also noted that parents and their children often identified similar issues, which is an important factor to be considered in developing child-report and parent-proxy report measures of functioning.

Task 2: Administer preliminary items to sample of NF1 patients and parents and use item analysis methods to construct preliminary HRQL instrument

- *Recruit NF1 participants and parents.* We successfully recruited 83 children with NF1 between the ages of 8 and 17 years, and 83 parents of children with NF1 to complete the first generation health-related quality of life instrument (developed in Task 1).
- *Mail out questionnaires for completion and return.* 83 completed questionnaire packets from children with NF1 and 83 completed questionnaire packets from parents of children with NF1 were received for analysis.
- *Enter and analyze data.* All data from children and parents were entered into SPSS v13 for statistical analysis. This included parent and child responses to the HRQL instrument, ratings of disease severity, and demographic information.

- *Produce final NF1-specific instrument for studies in subsequent tasks.* The revised version of the NF1-specific HRQL instrument was prepared based on information and comments collected in this task. This version was used to complete Task 3.

Results and Discussion of Research Activities in Task 2. The primary findings from Task 2 related primarily to the descriptiveness, understandability, and general psychometric properties of the first generation NF1-specific HRQL instrument. Parents and children completed parallel versions of the instrument, which were identical with the exception of wording (“I have.....” vs. “my child has...”).

Subjects. We recruited 83 children with NF1 between the ages of 8 and 17 years, and 83 parents of children with NF1 to complete the questionnaire, for a total of 166 participants. We recruited 40 males and 40 females (3 participants did not identify gender). Adult ratings of disease severity indicated that the majority of the sample fell into the mild range of severity (Riccardi scale) and the mild range of visible impact (Ablon scale), suggesting that while there was a wide range of severity in our sample, as a group were mildly affected.

Missing Data, Clarity, Burden and Descriptiveness. Because of our interest in the feasibility of employing an instrument such as this, we were interested in a number of related variables, including missing data (perhaps reflective of poor wording or a difficult to understand question), as well as informant-completed ratings of burden associated with completing the questionnaire and overall descriptiveness of the questions in terms of that individual’s health-related quality of life. For child informants, there were minimal missing data (<3%), <1% of responses for which the informant indicated that the question was not clear, and the average rating of burden associated with completing the instrument was minimal, with mean difficulty ratings of 4.3 and 4.5 (child and parent, respectively), and mean upset ratings of 4.3 and 4.6 (child and parent, respectively) out of 5 (5 = not at all). For adult informants, there were minimal missing data (<3%), <1% of responses that for which the informant indicated that the question was not clear, and the average rating of burden associated with completing the instrument was minimal. Both parent and child informants rated the item content as “good” in terms of how descriptive these items were of the child’s overall health-related quality of life. However, it should be noted that child informants did require some degree of assistance, with 67% reporting help from an adult (mother or father).

General Psychometric Properties. For the purposes of this task, we examined the psychometric properties of the first generation instrument by examining the descriptive statistics of the items and subscales (dispersion, central tendency) and the internal validity of the subscales (Cronbach’s *alpha*).

Internal validity. The internal validity of a scale measures the extent to which the items are measuring a uniform construct or domain, such as social functioning or behavior problems. Table 1 below presents the *alpha* coefficients for each subscale of the instrument. In general, these data suggest that the scale demonstrates satisfactory internal consistency/reliability.

TABLE 1: Coefficient *alpha* (Internal Consistency) for each subscale by informant.

Subscale	# of Items	Parent Informant	Child Informant
Appetite and Sleep	4	.583	.388
Pain	8	.866	.802
Understanding	2	.621	.619
Sensation	3	.421	.458
Symptoms	12	.847	.865
Psych and Behavior	25	.886	.856
School & Cognition	17	.957	.920
Social Relations	10	.805	.816
Appearance	10	.927	.882
Speech & Language	2	.585	.714

Descriptive statistics. Descriptive statistics for each item are presented in Table 2 for both parents and children. As can be seen, the majority of items yielded a range of responses from both groups of informants.

Table 2: Child and Parent Informant Mean Ratings for Each Item.

Item Descriptor	Item Code	Child Mean	Parent Mean
In general my health is	GH1	4.01	3.76
Compared to this time last year my health is	GH2	3.80	3.57
Sick more easily than other kids	GH3	3.81	3.93
Had difficulty falling asleep/staying asleep	AS1	3.22	3.29
Had bad dream	AS2	4.22	4.22
Been less hungry	AS3	3.95	3.98
Been hungrier	AS4	3.62	3.79
Bothered that didn't know enough about NF	U1	4.25	4.55
Frustrated about having NF	U2	3.69	3.70
Had difficulty hearing others	SE1	4.31	4.41
Wears hearing aide	SEHA	0	0.05
Had trouble seeing	SE2	4.13	4.09
Wears glasses/contacts	SEGC	0.31	0.3
Had trouble feeling things	SE3	4.81	4.80
Hurt a lot	P1	3.94	3.90
Had muscle pains	P2	3.78	3.61
Had headaches	P3	3.59	3.57
Has stomachaches	P4	3.65	3.72
Had pain in bones or joints	P5	4.05	3.85
Had neurofibromas or other areas hurt to touch	P6	4.36	4.17
Compared to others my age the amount of pain is	P7	3.04	2.58
Pain keeps me from doing things want to do	P8	4.03	4.06
Felt sick to stomach	SY1	3.84	3.88
Had a headache	SY2	3.70	3.52
Had stomachache	SY3	3.72	3.71
Had a hard time breathing	SY4	4.53	4.59
Felt dizzy	SY5	4.23	4.65
Felt weak	SY6	4.23	4.47

Felt tired or fatigued	SY7	3.33	3.48
Had a hard time swallowing	SY8	4.58	4.76
Had a hard time keeping balance	SY9	4.25	4.30
Had difficulty tying shoes, using scissors	SY10	4.39	4.10
Been clumsy	SY11	4.03	3.62
Had a hard time riding a bike	SY12	3.89	3.72
Felt cranky	PB1	3.37	3.13
Worried	PB2	3.62	3.53
Anxious	PB3	3.62	3.54
Gotten easily frustrated	PB4	2.90	2.93
Gotten in trouble because of behavior @ school	PB5	4.35	4.09
Gotten in trouble because of behavior @ home	PB6	3.48	3.45
Felt afraid/scared	PB7	4.01	3.95
Felt sad, down or depressed	PB8	3.85	3.78
Felt angry	PB9	3.51	3.33
Worried about what might happen to me	PB10	3.85	3.90
Felt like crying	PB11	4.02	3.95
Felt lonely	PB12	3.95	3.98
Felt cheerful	PB13	2.14	2.44
Felt confident	PB14	2.32	2.61
Enjoyed things	PB15	1.90	2.19
Had fun	PB16	1.77	2.16
Felt jittery or restless	PB17	3.47	3.76
Argued	PB18	3.04	2.81
Wanted to be alone	PB19	3.59	3.54
Had mood swings	PB20	3.49	3.08
Not done what was asked	PB21	3.68	3.31
Had anxiety or panic attacks	PB22	4.61	4.6
Hit or kicked someone	PB23	4.14	4.11
Heard voices that weren't there	PB24	4.65	4.93
Compared to others, behavior is	PB25	3.69	3.34
Missed school because of health	SC1	4.21	4.36
School on vacation	SC1A	1	1
Been bothered because missed school	SC2	4.41	4.38
Hasn't missed any school	SC2A	1	1
Missed school to go to doctor or hospital	SC3	4.08	4.01
Had difficulty solving math	SC4	3.40	2.87
Had difficulty writing papers or reports	SC5	3.52	2.52
Had trouble following or understanding directions	SC6	3.69	2.96
Had difficulty remembering what read	SC7	3.45	2.88
Had trouble reading	SC8	3.87	3.16
Forgotten things	SC9	3.56	3.02
Had trouble keeping up with schoolwork	SC10	3.70	2.95
Had trouble turning schoolwork in on time	SC11	3.90	3.29
Had difficulty paying attention and concentrating	SC12	3.66	3.05
Had trouble writing neatly	SC13	3.11	2.38
Had a hard time sitting still in class	SC14	3.76	3.35
Had trouble organizing work or things	SC15	3.55	2.70
Had trouble spelling	SC16	3.43	2.71
How would you rate your ability to do	SC17	3.70	2.96

schoolwork			
Had trouble getting along with other kids	SR1	4.15	3.88
Helped others	SR2	2.32	2.43
Preferred to be alone	SR3	3.63	3.59
Preferred quiet activities	SR4	3.53	3.22
Avoided doing things with other kids	SR5	4.17	3.95
Felt bothered because couldn't do activities liked	SR6	3.56	3.56
Felt like other kids didn't want to do things with them	SR7	3.61	3.46
Felt like other kids didn't want to be friend	SR8	3.9	3.38
How would you rate your family's ability to get along	SR9	3.80	3.83
How would you rate your ability to get along w/others	SR10	4.04	3.60
Been teased about how look	A1	4.07	3.94
Felt bad about appearance	A2	3.94	3.93
Worried about looks	A3	3.95	3.79
Been teased about size	A4	4.21	3.86
Avoided doing things w/others because of looks	A5	4.53	4.45
Done things to hide part of body because of looks	A6	4.25	4.19
Noticed people staring	A7	4.33	4.17
Heard strangers make rude comments	A8	4.55	4.23
Worried about other people teasing them	A9	3.84	3.71
Am satisfied with looks	A10	3.73	3.54
People had hard time understanding me when talk	SL1	3.5	3.36
I had a hard time understanding what other people say	SL2	4.15	3.94
How well did questions describe quality of life	GR1	3.82	3.55
How would you rate your overall quality of life	GR2	3.9	3.78
How difficult was it to complete this survey	GR3	4.27	4.46
How upsetting was it to complete this survey	GR4	4.31	4.59

Overall, the data gathered in this phase indicate that we were able to include item content that was reliable and generally descriptive of children's health-related quality of life. Additionally, participants did not perceive the instrument as being burdensome or upsetting to complete. Several items which were difficult for a small number of participants to understand were re-written for the revision of the instrument used in Task 3.

Task 3: Conduct reliability, validity and responsivity studies for NF1 instrument

- *Recruit NF1 participants and parents.* We recruited 21 children with NF1 between the ages of 8 and 17 years, and 21 parents of children with NF1 to complete the questionnaires at two time intervals. Parents completed the NFqol-Parent Proxy instrument, standardized measures of child health-related quality of

- life (PedsQL), emotional functioning (Conners Parent Questionnaire), a variety of single-item ratings of health, quality of life and NF1 severity), as well as sociodemographics.
- *Mail out initial set of questionnaires for completion and return.*
 - *Mail out followup set of questionnaires for completion and return.* We received 21 completed informant pairs of questionnaires (child and parent) that were analyzable.
 - *Analyze data to describe the psychometric properties of the NF1-specific instrument (“NFqol”).* Analyses have been completed and presented below which describe the reliability (test-retest and coefficient *alpha*/internal consistency) and validity (correlation with other measures) of the NFqol.

Results and Discussion of Activities from Task 3. The primary findings during this final period relate to the psychometric properties of the NFqol instrument. We were specifically interested in the test-retest reliability, internal consistency, cross-informant reliability, and validity of this instrument. Children with NF1, and their parents, completed parallel versions of the NFqol at two points in time. Additionally, parents completed a variety of standardized child behavior and functioning measures, which were used in the validity studies.

Subjects. We recruited 21 children with NF1 between the ages of 8 and 17 years and 21 parents of children with NF1 to complete the NFqol instrument, for a total of 42 participants in this phase. For child informants, there were 15 males and 6 females; gender was not collected for parent informants. The mean child age was 12.83 ($sd = 2.54$). Severity and visibility ratings for the child informants are presented in Table 3, and it can be seen that the majority of children were mild-moderate in the severity NF1, with minimal visibility of the condition. The majority of the parent informants were Caucasian and married. Table 4 presents the demographic characteristics of the parent informants.

Table 3. Characteristics of Child Participants

Variables		N	%
Gender	M	15	71.4
	F	6	28.6
Visibility*	1	12	60
	2	7	35
	3	5	5
Severity**	1	9	45
	2	9	45
	3	2	10
Age		Mean	Std
		12.83	2.54

Note: *Parent rating of Visibility was from 1-5 (1=mild)

**Parent rating of Severity was from 1-5 (1=mild)

Table 4. Characteristics of Parent Participants

Variables		N	%
Race	Asian	2	9.5
	White	17	81
	Other	2	9.5
Hispanic	No	19	90.4
	Yes	1	4.8
Marital status	Never Married	1	4.8
	Married	17	80.9
	Divorced	2	9.5
	Widowed	1	4.8
Education	Graduate high school	2	9.5
	Part of college	4	19
	Graduate college	11	52.3
	Graduate graduate school	4	19
Education (Spouse)	Part of high school	1	4.8
	Graduate high school	3	14.3
	Part of college	4	19
	Graduate college	9	42.9
	Graduate graduate school	2	9.5
Income	10K~15K	3	14.3
	25K~50K	2	9.5
	50K~65K	3	14.3
	65K~80K	4	19
	>80K	9	42.9

Measures. Child participants completed the following instruments: (1) *NFqol-Child*, a 100-item self-report measure developed specifically for this project. Informants rate the frequency of each statement over the past 7 days; (2) *PedsQL Teen Report* for participants between the ages of 13 and 17 (Varni, Seid & Rode, 1999); (3) *Conners-Wells Self-Report Scale* (Conners & Wells, 1997), a standardized measure of child behavioral functioning for participants between the ages of 12 and 17. Parent participants completed: (1) *NFqol-Parent*, a parallel version of the child measure listed above; (2) *Conners' Parent Rating Scale-Revised* (Conners, 2002), an 80-item standardized measure of child behavioral functioning; (3) *PedsQL-Parent Report* (Varni, Seid & Rode, 1999), a parallel measure to the child report listed above; (4) *Play-Performance Scale for Children* (Lansky et al., 1987), a single-item rating of child activity during the past 7 days; and (5) single-item ratings of severity of NF1 and visibility of NF1. The data were entered and analyzed using SPSS 15.0.

NFqol Item Descriptive Statistics. [NOTE: Table 5 provides a listing NFqol items and variable labels. Table 6 provides similar information for the NF-qol subscales, and Table 7 includes a listing of the single-item ratings and associated variable labels.]

Table 8 presents the descriptive statistics for the NFqol-Child instrument. For each item, the mean, standard deviation, and minimum/maximum values are presented. Similar information for the NFqol-Parent is also presented in this Table.

At the level of the item, it can be seen that the majority of items demonstrated satisfactory performance in terms of ceiling/floor effects and range, for both sets of informants. That is, with minimal exceptions, items on the parent- and child-report versions demonstrated variability and were not uniformly rated as always or never occurring.

Items for which limited variability was notable included: (a) *difficulty feeling things* [SE3; parent- and child-report min/max = 4/5]; (b) *hearing voices that weren't present* [PB24; parent-report min/max = 4/5]; (c) and *strangers made rude comments* [A8; child-report min/max = 4/5].

The NFqol data were also examined using subscale-level reports. Subscales were rationally constructed of similar item content. Subscale scores were calculated by two different methods: (1) simple sum of the ratings for each item, and (2) mean rating for each item within the subscale.

Table 9 presents the descriptive statistics for the NFqol subscales, for both parents and children. At the level of the subscale, no significant restrictions were noted on data from either respondent. Minimum and maximum values for subscales calculated by summation and by mean rating demonstrated adequate variability, with no scales demonstrating restricted ranges.

NFqol Reliability Analyses. Three different analyses were conducted to examine the reliability of the NFqol parent- and child-report instruments.

(1). Internal consistency (Cronbach's *alpha*), a measure of the extent to which items reflect similar content or construct was computed for each of the subscale mean ratings, and is reported in Table 10. In general, *alpha* coefficients of $\geq .70$ are considered adequate for group comparisons (Nunnally & Bernstein 1994). In general, the subscales demonstrated adequate internal consistency, as measured by this criterion. Subscales that performed poorly included: (a) *enjoyment* [PB1316; parent- and child-report *alpha* .67 and .42, respectively]; (b) *problem behavior-II* [PB1724; parent-report *alpha* = .66]; and (c) *writing neatly* [SC13; child-report *alpha* = .58].

(2). The reliability (or stability) of the NFqol over time (test-retest reliability) was also assessed. Parent and child informants completed the appropriate NFqol version a second time, approximately 4 weeks after the initial response. Constructs (or subscales) that are understood to be relatively static, are expected to demonstrate high reliability across the time interval, as reflected in the resulting Pearson correlation coefficient. Constructs that are understood to be relatively dynamic (e.g., mood rating) are expected to demonstrate poorer correlations across time.

Table 11 presents the results of the correlational analyses for the NFqol subscales completed at Time 1 and Time 2. Subscales demonstrating the poorest stability over time included: (a) *enjoyment* [PB1316; parent- and child report correlations = .55 and .28, respectively; (b) *problem behavior-II* [PB1724; parent- and child-report correlations = .51 and .68, respectively]; and (c) *writing neatly* [SC13; child-report correlation = .44].

(3). Cross informant reliability was assessed by examining the association between child and parent reports on each subscale. In general, the patient's report is considered to be the "gold standard" for quality of life information; proxy reporters may have limited information regarding certain aspects of the patient's quality of life (e.g., internal mood states), thereby lowering the resulting association. Achenbach and his colleagues have demonstrated that parents and children typically evidence good agreement on external, observable behaviors, but poor agreement on internal states, such as anxiety or depression. Table 12 presents the cross informant correlations for each of the NFqol subscales. With the exception of the *enjoyment* scale [PB1316; $r = .1588$, $p = .459$], cross informant reports on all subscales were significantly correlated (all $ps < .10$). These significant correlations are consistent with strong agreement across child and parent reports.

NFqol Validity Analyses. The validity of the NFqol was evaluated by examining the relationship between NFqol subscale scores and previously standardized measures of HRQOL and functioning. Validity is an iterative process, and these analyses represent initial documentation of the properties of this NF1-specific instrument. Evidence supporting the validity of this instrument will be examined in regard to correlations with similar types of measures (e.g., correlation of NFqol subscale regarding physical functioning with PedsQL physical functioning subscale) for which there is hypothesized to be a significant positive relationship, and correlations with subscales which would not be hypothesized to be strongly related (e.g., NFqol physical functioning subscale and the Conners subscale reflecting attention deficit hyperactivity disorder). Correlations with the PedsQL (youth- and parent-report), Conners scales (youth- and parent-report), and Play-Performance Scale (parent-report) were used to investigate the validity of the NFqol. Single-item correlations were also examined, including the relationship of the NFqol subscales to ratings of general health, visibility and severity ratings, and demographic characteristics.

(1). The construct validity of the NFqol was examined by computing the correlation between NFqol subscale scores and each of the PedsQL subscales for child and parent informants. Tables 13 and 14 present the results of the parent-report and child-report analyses, respectively.

Examination of the parent-report correlations indicates significant relationships between similar NFqol and PedsQL subscales, in the expected direction (note that higher scores on the NFqol indicate higher functioning, while the PedsQL was scored such that higher scores were indicative of more frequent problems). Specifically, the NFqol Physical Symptoms subscale was significantly correlated with the PedsQL Physical

Functioning subscale ($r = -0.501$, $p = .02$), the NFqol Academic Problem subscale was significantly correlated with the Educational Functioning subscale of the PedsQL ($r = -0.83$, $p < .0001$), and the two Problem Behavior scales from the NFqol were significantly correlated with the PedsQL Emotional Functioning scale ($r = -0.87$ and -0.83 , $p < .0001$, respectively). Although these correlations are significant and in the expected direction, it should be noted that there were many instances in which the NFqol subscales also evidenced significant correlation with other theoretically unrelated PedsQL subscales. This finding suggests that the NFqol subscales are not as specific as would be desired in regard to the construct being measured.

Examination of the child-report correlational analyses is similar to that reported above with the parent scales. That is, although the NFqol subscales were significantly associated with the parallel PedsQL subscales, there was substantial lack of specificity in those correlations, perhaps suggesting that a more general functioning level was being assessed by the NFqol.

(2) The construct validity of the NFqol was further examined by computing the correlation between the NFqol subscale scores and each of the Conners subscales for parent and child informants. These analyses are provided in Tables 15.

Examination of the NFqol-Parent Problem Behavior subscales (I and II) correlations with the Conners subscales indicates significant relationships in the expected directions. For example, the Problem Behavior-I subscale, which largely taps internalizing problems, is significantly correlated with Conners subscales reflecting similar content, although consistent with the findings from the PedsQL correlations, the NFqol appear to demonstrate a lack of specificity and yield significant correlations with most Conners scales.

This same pattern was also identified in the child-report data. That is, although there were significant correlations with similar Conners-Wells subscales, the NFqol subscales also correlated more generally with the other instrument. In addition to the potential lack of specificity, it may also be the case that the NFqol is tapping into an underlying dimension of distress.

(3) The validity of the NFqol was further investigated by examining the relationship between NFqol subscales and a number of single-item and demographic variables. Ideally, the NFqol scores would not be significantly related to demographic variables, such educational status or income. However, NFqol scores may be expected to relate to severity and/or visibility ratings, Play-Performance Scale scores, or ratings of overall health and wellness.

Table 16 presents the findings of the NFqol-Parent subscales and the single-item variables. It can be seen that school attendance (SC132), internalizing problem behavior (PB112), and understanding of NF1 were significantly correlated with overall health status (GH1). Parents provided a single-item of their child's overall quality of life (GR2), and this was not significantly related to any of the NFqol subscales. Parent rating of function status (Play-Performance scores) were significantly correlated with a number of

NFqol subscales, including appetite (AS34), understanding (U12), internalizing problem behavior (PB112), and externalizing problem behavior (PB1724). However, functional status scores were not significantly related to social relations (SR18), school attendance (SC132), physical symptoms (SY112), pain (P18), or sleep (AS12).

Table 17 presents the findings for the NFqol-Child subscales and the single-item variables. The child's rating of their overall quality of life (GR2) was significant correlated with a number of NFqol subscales, including understanding of NF1 (U12), internalizing problem behaviors (PB112), enjoyment (PB1316), externalizing problem behaviors (PB1724), academic problems (SC416), social relations (SR18), and teasing (A19). Note that these correlations are all positive, indicating that higher scores on the NFqol (higher functioning, or less problems) were associated with higher overall quality of life ratings.

Child informant ratings of general health (GH1) were significantly related to a number of NFqol subscales as well. These included sleep (AS12), understanding of NF1 (U12), physical symptoms (SY112), enjoyment (PB1316), externalizing problem behaviors (PB1724), school attendance (SC132), academic problems (SC416), and social relationships (SR18).

Parent ratings of the child's NF1 severity were significantly related to the child's self-report of sleep (AS12), externalizing problem behaviors (PB1724), and school attendance (SC132). Parent ratings of NF1 visibility significantly related to the child's report of sleep (AS12) and pain (P18).

NFqol Acceptability and Burden Ratings. Single-item ratings were also included to assess informant acceptability and the burden associated with completing the NFqol. Parents and children rated the NFqol as being not very difficult to complete ($M = 4.29$ and 4.38 , respectively, on a 5-point scale) and not very upsetting ($M = 4.0$ and 4.57 , respectively). Parents rated the NFqol content as good descriptors of the child's quality of life ($M = 4.05$), while children rated the content somewhat lower ($M = 3.43$). These ratings indicate that the NFqol was not perceived as being particularly burdensome by parent or child respondents; however the ratings also suggest that there were aspects of quality of life that were not assessed by the instrument.

3. KEY RESEARCH ACCOMPLISHMENTS

This project illustrated the process for developing a measure of health-related quality of life developed specifically for children with NF1. Children with NF1 and their parents, as well as health care providers and teachers, served as the content experts for this measure. These experts participated in individual interviews to identify important item content and pilot instruments were developed for testing and revision. The initial version of the instrument was pilot tested and refined, based on psychometric analysis and comments. The resulting version of the NF1-specific instrument (*NFqol*) was then completed by a sample of children and parents to investigate the reliability and validity of the measure.

Key findings included:

- The NFqol-Parent and NFqol-Child report versions demonstrate adequate test-retest reliability coefficients over a one-month reporting interval;
- The NFqol-Parent and NFqol-Child report versions demonstrated adequate internal consistency at the level of the subscale;
- Subscale scores from the NFqol-Parent and NFqol-Child report versions generally correlated in the expected directions with similar scales of previously standardized instruments, demonstrating construct validity. However, the correlations with other measures were also noted to be somewhat nonspecific, suggesting that a more generalized aspect of functioning.
- The instruments were each rated as acceptable to informants, meaning that the instruments were not perceived as particularly burdensome or distressing to complete.

4. REPORTABLE OUTCOMES: There have been no publications from these data at this point.

5. CONCLUSIONS

This project demonstrated that a reliable and valid self-report measure of health-related quality of life could be developed specifically for youth with NF1 and their parents. The potential advantage of this instrument is the inclusion of item content that was identified as important by children with NF1 themselves, and their parents. Anecdotal examination of the item however, would suggest that there was actually a relatively small number of items that were truly unique to this population. A substantial number of items and domains were consistent with those included in other, more generic measures of HRQL, and it may be the case that the amount of unique information gained in using the NFqol is minimal. The NFqol does include more coverage of items related to teasing for example, but coverage of school performance, social relations, and physical functioning tends to be somewhat universal across instruments. Importantly, although the item content was developed with children, parents, and health care providers, informants rated the final instrument as being a “good” but not excellent description of their quality of life. The apparent lack of specificity of the subscales, in spite of good reliability, suggests that the measure may be tapping into a more generalized dimension of functioning or distress, as opposed to dimensions that are unique to this population.

6. REFERENCES

- Conners CK (2002). Conner’s parent rating scale-revised (L). Toronto ON: Multi-Health Systems, Inc.
- Conners CK & Wells K (1997). Conners-Wells self-report scale (S). Toronto ON: Multi-Health Systems, Inc.
- Goldberg Y, Dibbern K., Klein J, Riccardi VM, Graham JM (1996). Neurofibromatosis Type 1: An update and review for the primary pediatrician. *Clinical Pediatrics (Phila)*, 35, 545-561.

- Koth CW, Cutting LE, & Denckla MB (2000). The association of neurofibromatosis Type 1 and Attention Deficit Hyperactivity Disorder. *Child Neurology*, 6, 185-194.
- Lansky SB et al. (1987). The measurement of performance in childhood cancer patients. *Cancer*, 60 (7), 1651-1656.
- Moore BD, Slopis JM, Schomer D, Jackson EF, & Levy B (1996). Neuropsychological significance of areas of high signal intensity on brain magnetic resonance imaging scans of children with neurofibromatosis. *Neurology*, 46, 1660-1668.
- North K, Riccardi V, Samango-Sprouse C, Ferner R, Moore BD, Legius E, Ratner N, & Denckla MB (1997a). Cognitive function and academic performance in neurofibromatosis 1: Consensus statement from the NF1 Cognitive Disorders Task Force. *Neurology*, 48, 1121-1127.
- North K, Riccardi V, Samango-Sprouse C, Ferner R, Moore BD, Legius E, Ratner N, & Denckla MB (1997b). Cognitive function and academic performance in neurofibromatosis 1: Significance of MRI abnormalities. *Neurology*, 44, 878-883.
- Nunnally JC & Bernstein IR (1994). *Psychometric theory* (3rd edition). New York: McGraw-Hill.
- Spaepen A, Borghgraef M, & Fryns J (1992). Von Recklinghausen-neurofibromatosis: A study of the psychological profile. In G. Evers-Kiebooms, J. Fryns, J. Cassiman, & H. Van den Berghe (Eds.), *Psychosocial aspects of genetic counseling: Birth defects* (pp. 85-91). New York: Wiley-Liss.
- Varni JW, Seid M, & Rode CA (1999). The PedsQL: Measurement model for the pediatric quality of life inventory. *Medical Care*, 37 (2), 126-139.
- Wadbsy M, Lindehammar H, & Eeg-Olofsson O (1989). Neurofibromatosis in childhood: Neuropsychological aspects. *Neurofibromatosis*, 2, 251-260.

7. APPENDICES

- a. NFqol-Child Report Instrument
- b. NFqol-Parent Report Instrument

8. LISTING OF INDIVIDUALS FUNDED BY THIS PROJECT

- A. Andrew S. Bradlyn, Ph.D.
- B. Carole V. Harris, Ph.D.
- C. Claire Bragonje, M.P.A.
- D. Erin Wilt, B.A.
- E. Susan Crayne

TABLE 5: NFqol Item Key

Label	Item
GH1	in general, I would say that my health is
GH2	compared to this time last year, I would say my health is
GH3	I get sick more easily than other kids
AS1	have diff falling asleep
AS2	had bad dream
AS3	been less hungry
AS4	been hungrier
U1	bothered that didn't know enough about NF
U2	frustrated about having NF
SE1	had diff hearing others
SEHA	wears hearing aid 1=Y 0=N
SE2	had trouble seeing
SEGC	wears glasses/contacts 1=Y 0=N
SE3	had trouble feeling things
P1	hurt a lot
P2	had muscle pains
P3	had headaches
P4	has stomachaches
P5	had pain in bones or joints
P6	had neurofibromas or other areas hurt to touch
P7	compared to other people my age, the amount of pain is
P8	pain keeps me from doing things wants to do
SY1	felt sick to stomach
SY2	had a headache
SY3	had a stomachache
SY4	had a hard time breathing
SY5	felt dizzy
SY6	felt weak
SY7	felt tired or fatigued
SY8	had a hard time swallowing
SY9	had a hard time keeping balance
SY10	had diff tying shoes, using scissors
SY11	been clumsy
SY12	had a hard time riding a bike
PB1	felt cranky
PB2	worried
PB3	anxious
PB4	gotten easily frustrated
PB5	gotten in trouble b/c behavior @ school
PB6	gotten in trouble b/c behavior @ Home

PB7	felt afraid/scared
PB8	felt sad, down or depressed
PB9	felt angry
PB10	worried about what might happen to me
PB11	felt like crying
PB12	felt lonely
PB13	felt cheerful
PB14	Felt confident
PB15	enjoyed things does
PB16	had fun
PB17	felt jittery or restless
PB18	argued
PB19	wanted to be alone
PB20	had mood swings
PB21	not done what was asked
PB22	had anxiety or panic attacks
PB23	hit or kicked someone
PB24	heard voices that weren't there
PB25	compared to other children, behavior is
SC1	missed school b/c of health
SC1a	was school on vacation
SC2	been bothered b/c missed school
SC2a	hasn't missed any school
SC3	missed school to go dr or hosp
SC4	had diff solving math
SC5	had diff writing papers or reports
SC6	had trouble following or understanding directions
SC7	had diff remembering what read
SC8	had trouble reading
SC9	forgotten things
SC10	had trouble keeping up with schoolwork
SC11	had trouble turning schoolwork in on time
SC12	had diff paying attention and concentrating
SC13	had trouble writing neatly
SC14	had a hard time sitting still in class
SC15	had trouble organizing work or things
SC16	had trouble spelling
SC17	how would you rate your ability to do schoolwork
SR1	had trouble getting along w/ other kids
SR2	helped others
SR3	preferred to be alone
SR4	preferred quiet activities
SR5	avoided doing things w/ other kids

SR6	felt bothered b/c couldn't do activities they like
SR7	felt like other kids didn't want to do things with them
SR8	felt like other kids didn't want to be friend
SR9	how would you rate your family's ability to get along
SR10	how would you rate your child's ability to get along with other kids
A1	been teased about how they look
A2	felt bad about appearance
A3	worried about looks
A4	been teased about size
A5	avoided doing things w/ others b/c of looks
A6	done things to hide part of body b/c of looks
A7	noticed people staring
A8	heard strangers make rude comments
A9	worried about other people teasing them
A10	I am satisfied w/ looks
SL1	other people had hard time understanding me when talk
SL2	I had a hard time understanding what other people say

TABLE 6: NFqol Subscale Key

Variable Label	Subscale Descriptor
AS12	Sleep
AS34	Appetite
U12	Understanding NF1
P18	Pain
SY112	Physical Symptoms
PB112	Problem Behavior-I Internalizing
PB1316	Happy/Enjoyment
PB1724	Problem Behavior-II Externalizing
SC13	School Attendance
SC416	Academic Problems
SR18	Social Relationships
A19	Teasing

Table 7: NFqol Single Item Rating

Variable Label	Item Descriptor
GH1	In general, I would say that my health is
GH2	Compared to this time last year, I would say my health is
GH3	I get sick more easily than other kids
GR1	How well did these questions describe your quality of life?
GR2	How would you rate your overall quality of life?
GR3	How difficult was it to complete this survey?
GR4	How upsetting was it to complete this survey?

Table 8. Item Descriptive Statistics for NFqol-Parent and NFqol-Child

Variable	Group	Mean	SD	Min	Max	N
GH1	Parent	3.76	0.77	3	5	21
	Child	3.76	0.77	2	5	21
GH2	Parent	3.48	0.60	3	5	21
	Child	3.90	0.77	3	5	21
GH3	Parent	3.62	1.28	1	5	21
	Child	3.76	1.37	1	5	21
AS1	Parent	3.48	1.21	1	5	21
	Child	3.24	1.18	1	5	21
AS2	Parent	4.33	0.80	3	5	21
	Child	4.14	1.01	2	5	21
AS3	Parent	4.10	1.18	1	5	21
	Child	3.76	1.41	1	5	21
AS4	Parent	3.95	1.14	2	5	20
	Child	3.67	1.32	1	5	21
P1	Parent	4.10	1.00	2	5	21
	Child	4.19	1.21	1	5	21
P2	Parent	3.62	0.97	2	5	21
	Child	3.62	1.20	1	5	21
P3	Parent	3.81	1.29	1	5	21
	Child	3.67	1.06	1	5	21
P4	Parent	3.86	1.28	1	5	21
	Child	4.05	1.20	2	5	21
P5	Parent	4	0.95	2	5	21
	Child	4.3	1.03	2	5	20
P6	Parent	3.7	1.62	1	5	21
	Child	4.14	1.31	1	5	21
P7	Parent	2.81	0.87	2	5	21
	Child	3.15	1.04	1	5	20
P8	Parent	3.90	1.09	2	5	21
	Child	3.76	1.34	1	5	21
U1	Parent	4.76	0.77	2	5	21
	Child	4.65	0.81	2	5	20
U2	Parent	3.71	1.19	1	5	21
	Child	3.65	1.46	1	5	20
SE1	Parent	4.38	0.86	2	5	21
	Child	4.67	0.66	3	5	21
SE2	Parent	4.14	1.35	1	5	21
	Child	4.62	0.92	2	5	21
SE3	Parent	4.95	0.22	4	5	21
	Child	4.95	0.22	4	5	21
SY1	Parent	3.95	1.20	2	5	21
	Child	4.24	1.00	2	5	21

SY2	Parent	4	1.14	2	5	21
	Child	4	1.18	1	5	21
SY3	Parent	4	1.22	2	5	21
	Child	4.24	1.00	2	5	21
SY4	Parent	4.38	1.02	2	5	21
	Child	4.52	0.87	2	5	21
SY5	Parent	4.24	0.99	2	5	21
	Child	4.25	0.91	3	5	20
SY6	Parent	3.86	1.15	2	5	21
	Child	4.43	0.98	2	5	21
SY7	Parent	3.52	1.29	2	5	21
	Child	3.71	1.19	2	5	21
SY8	Parent	4.52	0.87	2	5	21
	Child	4.76	0.54	3	5	21
SY9	Parent	3.86	1.28	1	5	21
	Child	4.48	0.87	2	5	21
SY10	Parent	3.43	1.40	1	5	21
	Child	4.38	1.16	1	5	21
SY11	Parent	3.38	1.43	1	5	21
	Child	3.86	1.39	1	5	21
SY12	Parent	3.14	1.42	1	5	21
	Child	4.05	1.20	1	5	21
PB1	Parent	3.19	0.93	2	5	21
	Child	3.48	1.03	2	5	21
PB2	Parent	3.86	1.20	1	5	21
	Child	3.95	1.16	1	5	21
PB3	Parent	3.90	1.18	1	5	21
	Child	4.05	1.16	1	5	21
PB4	Parent	2.95	1.24	1	5	21
	Child	3.43	1.29	1	5	21
PB5	Parent	4.57	0.87	2	5	21
	Child	4.90	0.44	3	5	21
PB6	Parent	3.62	1.02	2	5	21
	Child	3.95	1.07	2	5	21
PB7	Parent	4.05	1.20	1	5	21
	Child	4.05	1.36	1	5	21
PB8	Parent	3.71	1.31	1	5	21
	Child	4	1.30	1	5	21
PB9	Parent	3.43	1.08	1	5	21
	Child	3.81	1.17	1	5	21
PB10	Parent	4.14	1.15	1	5	21
	Child	4.15	1.27	1	5	20
PB11	Parent	3.67	1.24	1	5	21
	Child	3.86	1.20	1	5	21

PB12	Parent	3.62	1.16	1	5	21
	Child	4.45	0.82	3	5	20
PB13	Parent	2.57	1.16	1	5	21
	Child	2.43	1.29	1	5	21
PB14	Parent	2.81	1.21	1	5	21
	Child	2.43	1.21	1	5	21
PB15	Parent	2.43	1.29	1	5	21
	Child	1.52	0.68	1	3	21
PB16	Parent	2.33	1.11	1	5	21
	Child	1.57	0.60	1	3	21
PB17	Parent	3.76	1.22	2	5	21
	Child	3.85	1.18	1	5	20
PB18	Parent	2.71	0.90	1	5	21
	Child	3.33	1.06	1	5	21
PB19	Parent	3	1.14	1	5	21
	Child	3.57	1.29	1	5	21
PB20	Parent	3.38	1.43	1	5	21
	Child	3.38	1.16	1	5	21
PB21	Parent	3	1.10	1	5	21
	Child	3.38	1.07	1	5	21
PB22	Parent	4.57	0.92	2	5	21
	Child	4.76	0.54	3	5	21
PB23	Parent	4.43	0.81	2	5	21
	Child	4.57	0.75	3	5	21
PB24	Parent	4.95	0.22	4	5	21
	Child	4.76	0.70	2	5	21
PB25	Parent	3.62	1.02	2	5	21
	Child	3.52	0.75	2	5	21
SC1	Parent	4.5	0.78	3	5	18
	Child	4.43	0.87	3	5	21
SC2	Parent	4.5	1.21	1	5	16
	Child	4.58	1.02	1	5	19
SC3	Parent	4.5	0.98	2	5	18
	Child	4.10	1.18	2	5	21
SC4	Parent	3.15	1.27	1	5	20
	Child	3.76	1.37	1	5	21
SC5	Parent	2.5	1.60	1	5	20
	Child	3.24	1.37	1	5	21
SC6	Parent	3	1.38	1	5	20
	Child	3.71	1.35	1	5	21
SC7	Parent	3.05	1.54	1	5	20
	Child	3.38	1.46	1	5	21
SC8	Parent	3.35	1.50	1	5	20
	Child	3.81	1.36	1	5	21

SC9	Parent	3.05	1.36	1	5	20
	Child	3.24	1.34	1	5	21
SC10	Parent	3.15	1.72	1	5	20
	Child	3.57	1.43	1	5	21
SC11	Parent	3.35	1.53	1	5	20
	Child	3.90	1.22	1	5	21
SC12	Parent	2.75	1.52	1	5	20
	Child	3.62	1.28	1	5	21
SC13	Parent	2.6	1.60	1	5	20
	Child	2.67	1.56	1	5	21
SC14	Parent	3.45	1.19	1	5	20
	Child	4.09	1.18	1	5	21
SC15	Parent	2.45	1.43	1	5	20
	Child	2.95	1.69	1	5	21
SC16	Parent	2.65	1.50	1	5	20
	Child	3.28	1.31	1	5	21
SC17	Parent	2.95	1.22	1	5	19
	Child	3.43	1.03	2	5	21
SR1	Parent	4.28	0.96	2	5	21
	Child	4.43	1.03	2	5	21
SR2	Parent	2.19	1.03	1	4	21
	Child	2.57	0.92	1	4	21
SR3	Parent	3.43	1.08	1	5	21
	Child	3.71	1.23	1	5	21
SR4	Parent	3.05	1.02	1	5	21
	Child	3.57	1.25	1	5	21
SR5	Parent	3.81	1.12	2	5	21
	Child	3.90	1.14	2	5	21
SR6	Parent	3.62	1.28	1	5	21
	Child	3.85	1.50	1	5	20
SR7	Parent	3.95	1.12	2	5	21
	Child	4	1	2	5	21
SR8	Parent	3.90	1.04	2	5	21
	Child	4.10	1.18	2	5	21
SR9	Parent	4	0.55	3	5	21
	Child	3.76	0.89	2	5	21
SR10	Parent	3.95	0.92	2	5	21
	Child	4.10	1.00	2	5	21
A1	Parent	4.38	0.92	2	5	21
	Child	4.33	1.15	1	5	21
A2	Parent	4.24	0.89	2	5	21
	Child	4.28	1.19	1	5	21
A3	Parent	3.90	1.22	2	5	21
	Child	4.28	1.19	1	5	21

A4	Parent	4.10	1.26	2	5	21
	Child	4.28	1.19	1	5	21
A5	Parent	4.57	0.87	2	5	21
	Child	4.57	0.75	3	5	21
A6	Parent	4.43	1.03	2	5	21
	Child	4.55	0.89	2	5	20
A7	Parent	4.19	0.98	2	5	21
	Child	4.43	0.81	3	5	21
A8	Parent	4.71	0.64	3	5	21
	Child	4.81	0.40	4	5	21
A9	Parent	4.04	1.12	2	5	21
	Child	3.95	1.24	1	5	21
A10	Parent	3.76	1.00	2	5	21
	Child	3.90	1.22	1	5	21
SL1	Parent	3.57	1.21	1	5	21
	Child	3.71	0.90	2	5	21
SL2	Parent	4.43	1.03	2	5	21
	Child	4.33	0.73	3	5	21
GR1	Parent	4.05	0.74	3	5	21
	Child	3.43	0.87	2	5	21
GR2	Parent	4.43	0.75	3	5	21
	Child	4.05	0.97	2	5	21
GR3	Parent	4.29	1.19	1	5	21
	Child	4.38	0.80	3	5	21
GR4	Parent	4	0.84	2	5	21
	Child	4.57	0.75	3	5	21

Table 9. Summary Descriptive Statistics for NFqol-Parent and NFqol-Child Subscales

Variable	Group	Mean_Sum	SD	Min	Max	N	Mean_Rating	SD	Min	Max
AS12	Parent	7.81	1.86	5	10	21	3.90	0.93	2.5	5
	Child	7.38	1.88	4	10	21	3.69	0.94	2	5
AS34	Parent	8.2	1.79	6	10	20	4.1	0.90	3	5
	Child	7.43	2.04	2	10	21	3.71	1.02	1	5
U12	Parent	8.48	1.63	4	10	21	4.24	0.82	2	5
	Child	8.3	1.98	4	10	19	4.15	0.99	2	5
P18	Parent	29.9	6.05	19	38	20	3.74	0.76	2.38	4.75
	Child	31.2	6.36	19	40	19	3.90	0.80	2.38	5
SY12	Parent	46.28	10.3	25	60	21	3.86	0.86	2.08	5
	Child	51.3	7.50	37	60	20	4.28	0.62	3.08	5
PB112	Parent	44.71	9.99	22	58	21	3.73	0.83	1.83	4.83
	Child	48.42	10.89	22	60	19	4.04	0.91	1.83	5
PB1316	Parent	10.14	3.78	4	19	21	2.54	0.95	1	4.75
	Child	7.95	2.67	4	12	21	1.99	0.67	1	3
PB1724	Parent	29.81	5.27	19	38	21	3.73	0.66	2.38	4.75
	Child	31.5	4.55	23	40	20	3.94	0.57	2.88	5
SC132	Parent	13.44	2.31	8	15	16	4.48	0.77	2.67	5
	Child	12.95	2.39	9	15	19	4.32	0.80	3	5
SC416	Parent	38.5	15.42	13	65	20	2.96	1.19	1	5
	Child	45.24	13.38	22	64	21	3.48	1.03	1.69	4.92
SR18	Parent	28.24	5.58	19	38	21	3.53	0.70	2.38	4.75
	Child	30.3	5.49	22	38	20	3.79	0.68	2.75	4.75
A19	Parent	38.57	7.16	22	45	21	4.28	0.80	2.44	5
	Child	40.15	7.05	17	45	20	4.46	0.78	1.89	5

Table 10. NFqol-Parent and Child-Report Coefficient *alpha* Results

Variable	Informant	<i>alpha</i>
AS12_M	Parent	0.91
	Child	0.73
AS34_M	Parent	0.87
	Child	0.81
U12_M	Parent	0.86
	Child	0.87
P18_M	Parent	0.84
	Child	0.81
SY112_M	Parent	0.83
	Child	0.88
PB112_M	Parent	0.88
	Child	0.98
PB1316_M	Parent	0.67
	Child	0.42
PB1724_M	Parent	0.66
	Child	0.80
SC13_M	Parent	0.97
	Child	0.58
SC416_M	Parent	0.93
	Child	0.90
SR18_M	Parent	0.73
	Child	0.86
A19_M	Parent	0.93
	Child	0.95

Table 11. NFqol-Parent and Child-Report Test-Retest Analysis Results

Variable	Informant	Test-Retest <u>r</u>
AS12_M	Parent	0.84
	Child	0.58
AS34_M	Parent	0.78
	Child	0.68
U12_M	Parent	0.75
	Child	0.80
P18_M	Parent	0.74
	Child	0.68
SY112_M	Parent	0.90
	Child	0.80
PB112_M	Parent	0.78
	Child	0.95
PB1316_M	Parent	0.55
	Child	0.28
PB1724_M	Parent	0.51
	Child	0.68
SC13_M	Parent	0.94
	Child	0.44
SC416_M	Parent	0.88
	Child	0.82
SR18_M	Parent	0.58
	Child	0.75
A19_M	Parent	0.88
	Child	0.92

Table 12. Cross Informant Reliability Coefficients for NFqol

Variable	by Variable	Correlation	N	Probability
A19 parent	A19 child	0.6946	20	0.0007
AS12 parent	AS12 child	0.4783	21	0.0283
AS34 parent	AS34 child	0.5361	20	0.0148
P18 parent	P18 child	0.7321	18	0.0006
PB112 parent	PB112 child	0.7534	19	0.0002
PB1316 parent	PB1316 child	0.1588	21	0.4917
PB1724 parent	PB1724 child	0.7295	20	0.0003
SC13 2 parent	SC13 2 child	0.4607	15	0.084
SC416 parent	SC416 child	0.8444	20	<.0001
SR18 parent	SR18 child	0.7663	20	<.0001
SY112 parent	SY112 child	0.7006	20	0.0006
U12 parent	U12 child	0.4333	20	0.0564

Table 13. Correlation Coefficients for NFqol-Parent Subscales and PedsQL-Parent Subscales

Variable	By Variable	Correlation	N	Probability
A19	PQLPEDU	-0.4407	20	0.0518
A19	PQLPEMOT	-0.5339	20	0.0153
A19	PQLPPHYS	-0.4058	20	0.0758
A19	PQLPSOCI	-0.2363	20	0.3158
AS12	PQLPEDU	-0.5457	20	0.0128
AS12	PQLPEMOT	-0.7261	20	0.0003
AS12	PQLPPHYS	0.048	20	0.8408
AS12	PQLPSOCI	-0.0976	20	0.6824
AS34	PQLPEDU	-0.517	19	0.0234
AS34	PQLPEMOT	-0.7524	19	0.0002
AS34	PQLPPHYS	-0.2121	19	0.3833
AS34	PQLPSOCI	-0.166	19	0.497
P18	PQLPEDU	-0.2536	19	0.2949
P18	PQLPEMOT	-0.333	19	0.1635
P18	PQLPPHYS	-0.3004	19	0.2114
P18	PQLPSOCI	0.0964	19	0.6947
PB112	PQLPEDU	-0.7818	20	<.0001
PB112	PQLPEMOT	-0.8707	20	<.0001
PB112	PQLPPHYS	-0.4823	20	0.0313
PB112	PQLPSOCI	-0.3741	20	0.1042
PB1316	PQLPEDU	0.1388	20	0.5595

PB1316	PQLPEMOT	0.1985	20	0.4015
PB1316	PQLPPHYS	-0.4008	20	0.0799
PB1316	PQLPSOCI	-0.2246	20	0.341
PB1724	PQLPEDU	-0.6576	20	0.0016
PB1724	PQLPEMOT	-0.7134	20	0.0004
PB1724	PQLPPHYS	-0.2061	20	0.3834
PB1724	PQLPSOCI	-0.15	20	0.5278
SC13 2	PQLPEDU	-0.1272	15	0.6516
SC13 2	PQLPEMOT	-0.0061	15	0.9826
SC13 2	PQLPPHYS	-0.4189	15	0.1201
SC13 2	PQLPSOCI	-0.3689	15	0.176
SC416	PQLPEDU	-0.8338	19	<.0001
SC416	PQLPEMOT	-0.4209	19	0.0728
SC416	PQLPPHYS	-0.4617	19	0.0466
SC416	PQLPSOCI	-0.2365	19	0.3297
SR18	PQLPEDU	-0.7208	20	0.0003
SR18	PQLPEMOT	-0.6767	20	0.001
SR18	PQLPPHYS	-0.4593	20	0.0416
SR18	PQLPSOCI	-0.3993	20	0.0811
SY112	PQLPEDU	-0.4263	20	0.0609
SY112	PQLPEMOT	-0.4454	20	0.0491
SY112	PQLPPHYS	-0.5013	20	0.0243
SY112	PQLPSOCI	-0.1418	20	0.5509
U12	PQLPEDU	-0.5727	20	0.0083
U12	PQLPEMOT	-0.7287	20	0.0003
U12	PQLPPHYS	-0.2356	20	0.3174
U12	PQLPSOCI	-0.2651	20	0.2586

Table 14. Correlation Coefficients for NFqol-Child Subscales and PedsQL-Child Subscales

Variable	By Variable	Correlation	Count	Probability
AS12	PQLTHEAL	-0.522	20	0.0182
AS12	PQLTFEEL	-0.787	20	<.0001
AS12	PQLTOTHE	-0.5559	20	0.0109
AS12	PQLTEDU	-0.5437	19	0.0161
AS34	PQLTHEAL	-0.3636	20	0.1151
AS34	PQLTFEEL	-0.4346	20	0.0555
AS34	PQLTOTHE	-0.3443	20	0.1372
AS34	PQLTEDU	-0.4863	19	0.0348
U12	PQLTHEAL	-0.6572	19	0.0022
U12	PQLTFEEL	-0.5303	19	0.0195
U12	PQLTOTHE	-0.6365	19	0.0034
U12	PQLTEDU	-0.5488	18	0.0183
P18	PQLTHEAL	-0.5901	18	0.0099
P18	PQLTFEEL	-0.7659	18	0.0002
P18	PQLTOTHE	-0.5758	18	0.0124
P18	PQLTEDU	-0.5179	17	0.0332
SY112	PQLTHEAL	-0.6991	19	0.0009
SY112	PQLTFEEL	-0.7059	19	0.0007
SY112	PQLTOTHE	-0.495	19	0.0312
SY112	PQLTEDU	-0.467	18	0.0507
PB112	PQLTHEAL	-0.7578	18	0.0003
PB112	PQLTFEEL	-0.7454	18	0.0004
PB112	PQLTOTHE	-0.7071	18	0.001
PB112	PQLTEDU	-0.6166	17	0.0084
PB1316	PQLTHEAL	0.4701	20	0.0365
PB1316	PQLTFEEL	0.5407	20	0.0138
PB1316	PQLTOTHE	0.4671	20	0.0378
PB1316	PQLTEDU	0.6311	19	0.0038
PB1724	PQLTHEAL	-0.4715	19	0.0416
PB1724	PQLTFEEL	-0.4722	19	0.0412
PB1724	PQLTOTHE	-0.3953	19	0.0939
PB1724	PQLTEDU	-0.408	18	0.0928
SC13 2	PQLTHEAL	-0.1416	18	0.575
SC13 2	PQLTFEEL	-0.3794	18	0.1205
SC13 2	PQLTOTHE	-0.3574	18	0.1454

SC13 2	PQLTEDU	-0.534	17	0.0273
SC416	PQLTHEAL	-0.7494	20	0.0001
SC416	PQLTFEEL	-0.4544	20	0.0441
SC416	PQLTOTHE	-0.6546	20	0.0017
SC416	PQLTEDU	-0.7834	19	<.0001
SR18	PQLTHEAL	-0.7639	19	0.0001
SR18	PQLTFEEL	-0.551	19	0.0145
SR18	PQLTOTHE	-0.6339	19	0.0036
SR18	PQLTEDU	-0.7125	18	0.0009
A19	PQLTHEAL	-0.3428	19	0.1507
A19	PQLTFEEL	-0.3995	19	0.0902
A19	PQLTOTHE	-0.4888	19	0.0337
A19	PQLTEDU	-0.4366	18	0.0701

Table 15. Correlation Coefficients for NFqol-Parent Subscales and Conners Subscales

Variable	By Variable	Correlation	Count	Probability
AS12	CPADHD	-0.4369	21	0.0477
AS12	CPANX	-0.5172	21	0.0163
AS12	CPCOG	-0.4882	21	0.0248
AS12	CPDSMTOT	-0.4961	21	0.0222
AS12	CPEMOT	-0.4855	21	0.0257
AS12	CPHYPER	-0.0456	21	0.8444
AS12	CPHYPERI	-0.1362	21	0.5560
AS12	CPINATT	-0.5176	21	0.0163
AS12	CPOPP	-0.364	21	0.1048
AS12	CPPERFEC	-0.1977	21	0.3904
AS12	CPPSYCH	-0.3273	21	0.1476
AS12	CPRESTLE	-0.3601	21	0.1088
AS12	CPSOCIAL	-0.4216	21	0.0570
AS12	CPTOTAL	-0.4455	21	0.0430
AS34	CPADHD	-0.4819	20	0.0314
AS34	CPANX	-0.4736	20	0.0349
AS34	CPCOG	-0.5108	20	0.0214
AS34	CPDSMTOT	-0.5356	20	0.0149
AS34	CPEMOT	-0.5774	20	0.0077
AS34	CPHYPER	-0.1479	20	0.5338
AS34	CPHYPERI	-0.2631	20	0.2623
AS34	CPINATT	-0.5133	20	0.0206

AS34	CPOPP	-0.4837	20	0.0307
AS34	CPPERFEC	-0.3458	20	0.1354
AS34	CPPSYCH	-0.1889	20	0.4252
AS34	CPRESTLE	-0.383	20	0.0955
AS34	CPSOCIAL	-0.2087	20	0.3771
AS34	CPTOTAL	-0.4963	20	0.0260
U12	CPADHD	-0.3183	21	0.1597
U12	CPANX	-0.5951	21	0.0044
U12	CPCOG	-0.4399	21	0.0460
U12	CPDSMTOT	-0.3999	21	0.0725
U12	CPEMOT	-0.483	21	0.0265
U12	CPHYPER	0.0603	21	0.7951
U12	CPHYPERI	-0.0843	21	0.7164
U12	CPINATT	-0.4191	21	0.0586
U12	CPOPP	-0.2789	21	0.2208
U12	CPPERFEC	-0.4495	21	0.0409
U12	CPPSYCH	-0.5815	21	0.0057
U12	CPRESTLE	-0.2626	21	0.2502
U12	CPSOCIAL	-0.5758	21	0.0063
U12	CPTOTAL	-0.3868	21	0.0832
P18	CPADHD	-0.2475	20	0.2929
P18	CPANX	-0.3585	20	0.1206
P18	CPCOG	-0.3702	20	0.1081
P18	CPDSMTOT	-0.3513	20	0.1288
P18	CPEMOT	-0.2276	20	0.3344
P18	CPHYPER	-0.0771	20	0.7465
P18	CPHYPERI	-0.1179	20	0.6204
P18	CPINATT	-0.3312	20	0.1538
P18	CPOPP	-0.0684	20	0.7744
P18	CPPERFEC	-0.3668	20	0.1117
P18	CPPSYCH	-0.4568	20	0.0429
P18	CPRESTLE	-0.347	20	0.1339
P18	CPSOCIAL	-0.3249	20	0.1622
P18	CPTOTAL	-0.3516	20	0.1285
SY112	CPADHD	-0.3484	21	0.1217
SY112	CPANX	-0.3717	21	0.0971
SY112	CPCOG	-0.5121	21	0.0176
SY112	CPDSMTOT	-0.4268	21	0.0537
SY112	CPEMOT	-0.2295	21	0.3169
SY112	CPHYPER	-0.0669	21	0.7733
SY112	CPHYPERI	-0.1222	21	0.5977
SY112	CPINATT	-0.4459	21	0.0428
SY112	CPOPP	0.1294	21	0.5760
SY112	CPPERFEC	-0.1356	21	0.5578
SY112	CPPSYCH	-0.4522	21	0.0396
SY112	CPRESTLE	-0.3657	21	0.1030

SY112	CPSOCIAL	-0.255	21	0.2646
SY112	CPTOTAL	-0.3646	21	0.1042
PB112	CPADHD	-0.632	21	0.0021
PB112	CPANX	-0.7212	21	0.0002
PB112	CPCOG	-0.7178	21	0.0002
PB112	CPDSMTOT	-0.6895	21	0.0005
PB112	CPEMOT	-0.7008	21	0.0004
PB112	CPHYPER	-0.1583	21	0.4932
PB112	CPHYPERI	-0.3069	21	0.1760
PB112	CPINATT	-0.7203	21	0.0002
PB112	CPOPP	-0.3607	21	0.1082
PB112	CPPERFEC	-0.4152	21	0.0612
PB112	CPPSYCH	-0.5015	21	0.0205
PB112	CPRESTLE	-0.4804	21	0.0275
PB112	CPSOCIAL	-0.4777	21	0.0285
PB112	CPTOTAL	-0.6384	21	0.0018
PB1316	CPADHD	0.1894	21	0.4109
PB1316	CPANX	0.1486	21	0.5202
PB1316	CPCOG	0.1946	21	0.3981
PB1316	CPDSMTOT	0.2264	21	0.3236
PB1316	CPEMOT	0.0973	21	0.6748
PB1316	CPHYPER	-0.0538	21	0.8169
PB1316	CPHYPERI	0.0472	21	0.8390
PB1316	CPINATT	0.2464	21	0.2816
PB1316	CPOPP	0.2768	21	0.2245
PB1316	CPPERFEC	-0.0545	21	0.8145
PB1316	CPPSYCH	-0.0096	21	0.9671
PB1316	CPRESTLE	0.0958	21	0.6797
PB1316	CPSOCIAL	0.5433	21	0.0109
PB1316	CPTOTAL	0.1054	21	0.6492
PB1724	CPADHD	-0.5908	21	0.0048
PB1724	CPANX	-0.6276	21	0.0023
PB1724	CPCOG	-0.6348	21	0.0020
PB1724	CPDSMTOT	-0.6724	21	0.0008
PB1724	CPEMOT	-0.741	21	0.0001
PB1724	CPHYPER	-0.266	21	0.2438
PB1724	CPHYPERI	-0.3662	21	0.1026
PB1724	CPINATT	-0.6724	21	0.0008
PB1724	CPOPP	-0.717	21	0.0003
PB1724	CPPERFEC	-0.3593	21	0.1097
PB1724	CPPSYCH	-0.3405	21	0.1309
PB1724	CPRESTLE	-0.4301	21	0.0516
PB1724	CPSOCIAL	-0.4488	21	0.0413
PB1724	CPTOTAL	-0.6039	21	0.0037
SC13 2	CPADHD	0.1489	16	0.582

SC13 2	CPANX	0.0888	16	0.7436
SC13 2	CPCOG	0.0122	16	0.9641
SC13 2	CPDSMTOT	0.0923	16	0.7339
SC13 2	CPEMOT	-0.0559	16	0.8372
SC13 2	CPHYPER	0.0925	16	0.7333
SC13 2	CPHYPERI	0.1417	16	0.6007
SC13 2	CPINATT	0.0796	16	0.7696
SC13 2	CPOPP	0.2566	16	0.3375
SC13 2	CPPERFEC	-0.2353	16	0.3804
SC13 2	CPPSYCH	-0.0338	16	0.9011
SC13 2	CPRESTLE	0.1335	16	0.6221
SC13 2	CPSOCIAL	0.1037	16	0.7023
SC13 2	CPTOTAL	0.0566	16	0.8350
SC416	CPADHD	-0.7523	20	0.0001
SC416	CPANX	-0.3648	20	0.1138
SC416	CPCOG	-0.8791	20	<.0001
SC416	CPDSMTOT	-0.7683	20	<.0001
SC416	CPEMOT	-0.3353	20	0.1484
SC416	CPHYPER	-0.2799	20	0.2320
SC416	CPHYPERI	-0.4206	20	0.0648
SC416	CPINATT	-0.817	20	<.0001
SC416	CPOPP	-0.0732	20	0.7589
SC416	CPPERFEC	-0.1613	20	0.4968
SC416	CPPSYCH	-0.3007	20	0.1977
SC416	CPRESTLE	-0.5812	20	0.0072
SC416	CPSOCIAL	-0.2789	20	0.2338
SC416	CPTOTAL	-0.6181	20	0.0037
SR18	CPADHD	-0.4402	21	0.0458
SR18	CPANX	-0.5544	21	0.0091
SR18	CPCOG	-0.588	21	0.0051
SR18	CPDSMTOT	-0.5271	21	0.0141
SR18	CPEMOT	-0.436	21	0.0482
SR18	CPHYPER	-0.1181	21	0.6103
SR18	CPHYPERI	-0.2682	21	0.2399
SR18	CPINATT	-0.5425	21	0.0111
SR18	CPOPP	-0.2543	21	0.2659
SR18	CPPERFEC	-0.4011	21	0.0716
SR18	CPPSYCH	-0.5912	21	0.0048
SR18	CPRESTLE	-0.3605	21	0.1084
SR18	CPSOCIAL	-0.5368	21	0.0121
SR18	CPTOTAL	-0.4631	21	0.0345
A19	CPADHD	-0.458	21	0.0368
A19	CPANX	-0.3951	21	0.0763
A19	CPCOG	-0.4547	21	0.0384
A19	CPDSMTOT	-0.6301	21	0.0022
A19	CPEMOT	-0.3594	21	0.1095

A19	CPHYPER	-0.4304	21	0.0515
A19	CPHYPERI	-0.5642	21	0.0077
A19	CPINATT	-0.4805	21	0.0275
A19	CPOPP	-0.3237	21	0.1523
A19	CPPERFEC	-0.6603	21	0.0011
A19	CPPSYCH	-0.375	21	0.0939
A19	CPRESTLE	-0.5283	21	0.0138
A19	CPSOCIAL	-0.5106	21	0.018
A19	CPTOTAL	-0.5512	21	0.0096

Table 16. NFqol-Parent Correlations with Single-Item Variables

Variable	By Variable	Correlation	Count	Probability
AS12	INCOME	0.1558	21	0.4999
AS12	GH1	0.2465	21	0.2815
AS12	GH2	0.3084	21	0.1737
AS12	GH3	0.2612	21	0.2528
AS12	GR2	-0.0103	21	0.9647
AS12	PLAY	0.2090	21	0.3632
AS34	INCOME	0.3692	20	0.1092
AS34	GH1	0.1451	20	0.5415
AS34	GH2	0.2416	20	0.3049
AS34	GH3	0.3002	20	0.1984
AS34	GR2	0.0545	20	0.8196
AS34	PLAY	0.4055	20	0.0761
U12	INCOME	0.1299	21	0.5747
U12	GH1	0.4140	21	0.0621
U12	GH2	0.2668	21	0.2423
U12	GH3	0.2820	21	0.2156
U12	GR2	0.0293	21	0.8996
U12	PLAY	0.3684	21	0.1003
P18	INCOME	0.1518	20	0.5228
P18	GH1	0.3126	20	0.1796
P18	GH2	0.1433	20	0.5467
P18	GH3	0.1683	20	0.4781
P18	GR2	0.0218	20	0.9274
P18	PLAY	0.3537	20	0.1261
SY112	INCOME	0.1299	21	0.5746
SY112	GH1	0.2933	21	0.1970
SY112	GH2	0.2109	21	0.3587
SY112	GH3	0.0918	21	0.6922
SY112	GR2	-0.1273	21	0.5825
SY112	PLAY	0.1647	21	0.4755

PB112	INCOME	0.2277	21	0.3208
PB112	GH1	0.4792	21	0.0280
PB112	GH2	0.4064	21	0.0675
PB112	GH3	0.4356	21	0.0484
PB112	GR2	-0.0632	21	0.7854
PB112	PLAY	0.3928	21	0.0782
PB1316	INCOME	0.1768	21	0.4433
PB1316	GH1	-0.0909	21	0.6953
PB1316	GH2	-0.0753	21	0.7457
PB1316	GH3	-0.1426	21	0.5375
PB1316	GR2	0.1719	21	0.4562
PB1316	PLAY	0.0374	21	0.8723
PB1724	INCOME	0.4233	21	0.0559
PB1724	GH1	0.3340	21	0.1389
PB1724	GH2	0.2982	21	0.1892
PB1724	GH3	0.6245	21	0.0025
PB1724	GR2	-0.0672	21	0.7723
PB1724	PLAY	0.5838	21	0.0055
SC13 2	INCOME	0.1315	16	0.6273
SC13 2	GH1	0.6281	16	0.0092
SC13 2	GH2	0.3881	16	0.1374
SC13 2	GH3	-0.0549	16	0.8399
SC13 2	GR2	0.2642	16	0.3228
SC13 2	PLAY	0.0877	16	0.7466
SC416	INCOME	0.0293	20	0.9025
SC416	GH1	0.2089	20	0.3767
SC416	GH2	0.1181	20	0.6201
SC416	GH3	0.2448	20	0.2983
SC416	GR2	-0.2082	20	0.3783
SC416	PLAY	-0.1251	20	0.5991
SR18	INCOME	0.3400	21	0.1315
SR18	GH1	0.3056	21	0.1779
SR18	GH2	0.3372	21	0.1350
SR18	GH3	0.4674	21	0.0326
SR18	GR2	-0.3381	21	0.1339
SR18	PLAY	0.2346	21	0.3060
A19	INCOME	0.0374	21	0.8722
A19	GH1	0.4895	21	0.0243
A19	GH2	0.3516	21	0.1181
A19	GH3	0.6125	21	0.0032
A19	GR2	0.008	21	0.9725
A19	PLAY	0.3309	21	0.1429

Table 17. NFqol-Child Correlations with Single-Item Variables

Variable	By Variable	Correlation	Count	Probability
AS12	VR	-0.5035	20	0.0236
AS12	SR	-0.3888	20	0.0902
AS12	GH1	0.4458	21	0.0428
AS12	GH2	0.2681	21	0.2399
AS12	GH3	0.4615	21	0.0352
AS12	GR2	0.2078	21	0.3661
AS34	VR	-0.1918	20	0.4180
AS34	SR	-0.0827	20	0.7289
AS34	GH1	0.3237	21	0.1523
AS34	GH2	-0.2280	21	0.3203
AS34	GH3	0.1987	21	0.3878
AS34	GR2	-0.0612	21	0.7922
U12	VR	-0.2510	20	0.2858
U12	SR	0.2025	20	0.3919
U12	GH1	0.6943	20	0.0007
U12	GH2	0.2906	20	0.2138
U12	GH3	0.2084	20	0.3780
U12	GR2	0.4987	20	0.0252
P18	VR	-0.5063	18	0.0320
P18	SR	-0.1432	18	0.5709
P18	GH1	0.4639	19	0.0454
P18	GH2	0.4784	19	0.0383
P18	GH3	0.4407	19	0.0590
P18	GR2	0.5019	19	0.0286
SY112	VR	-0.2636	19	0.2755
SY112	SR	0.1710	19	0.4839
SY112	GH1	0.5306	20	0.0161
SY112	GH2	0.2060	20	0.3836
SY112	GH3	0.2214	20	0.3482
SY112	GR2	0.3289	20	0.1567
PB112	VR	-0.0451	19	0.8545
PB112	SR	0.3005	19	0.2113
PB112	GH1	0.4439	19	0.0569
PB112	GH2	0.5421	19	0.0165
PB112	GH3	0.1916	19	0.4319
PB112	GR2	0.7040	19	0.0008
PB1316	VR	-0.0492	20	0.8369
PB1316	SR	-0.0100	20	0.9666
PB1316	GH1	-0.4682	21	0.0323

PB1316	GH2	-0.5378	21	0.0119
PB1316	GH3	-0.3841	21	0.0856
PB1316	GR2	-0.5947	21	0.0045
PB1724	VR	0.0236	19	0.9236
PB1724	SR	0.4001	19	0.0896
PB1724	GH1	0.2527	20	0.2824
PB1724	GH2	0.1631	20	0.4921
PB1724	GH3	0.2875	20	0.2190
PB1724	GR2	0.4042	20	0.0771
SC13 2	VR	-0.3043	18	0.2196
SC13 2	SR	-0.5311	18	0.0233
SC13 2	GH1	0.4249	19	0.0698
SC13 2	GH2	0.2266	19	0.3509
SC13 2	GH3	0.6673	19	0.0018
SC13 2	GR2	0.3818	19	0.1067
SC416	VR	-0.2911	20	0.2130
SC416	SR	0.2277	20	0.3342
SC416	GH1	0.3753	21	0.0936
SC416	GH2	0.1871	21	0.4168
SC416	GH3	0.2369	21	0.3011
SC416	GR2	0.5748	21	0.0064
SR18	VR	-0.3508	19	0.1409
SR18	SR	0.1579	19	0.5185
SR18	GH1	0.6037	20	0.0048
SR18	GH2	0.3575	20	0.1217
SR18	GH3	0.4389	20	0.0529
SR18	GR2	0.4499	20	0.0466
A19	VR	0.0108	19	0.9651
A19	SR	0.2530	19	0.2961
A19	GH1	0.2609	20	0.2665
A19	GH2	0.2670	20	0.2552
A19	GH3	0.2342	20	0.3202
A19	GR2	0.6455	20	0.0021

NF-1 Health-Related Quality of Life

Version 2.0

Parent Report

Today's Date: _____

Directions:

Children with NF-1 sometimes have special problems. We are interested in **how much of a problem** these might have been for your child in the **PAST WEEK**. There are no right or wrong answers! Just circle the number that answers the question.

Thanks!

General Health

1. In general, I would say that my child's health is:	1	2	3	4	5
	Poor				Excellent
2. Compared to this time last year, I would say my child's health is:	1	2	3	4	5
	Much Worse				Much Better
3. My child gets sick more easily than other kids:	1	2	3	4	5
	Yes, Definitely				No, not at all

Appetite and Sleep

In the past week, has your child:

<u>in the past week, has your child:</u>	Always	Sometimes	Never		
4. Had difficulty falling asleep or staying asleep?	1	2	3	4	5
5. Had bad dreams or nightmares?	1	2	3	4	5
6. Been less hungry than usual?	1	2	3	4	5
7. Been more hungry than usual?	1	2	3	4	5

Pain

In the past week, has your child:

	Always	Sometimes	Never
8. Hurt a lot?	1	2	3
9. Has muscle pains or aches?	1	2	3
10. Had headaches?	1	2	3
11. Had stomachaches?	1	2	3
12. Had pain in his/her bones or joints?	1	2	3
13. Had neurofibromas or other areas on his/her body that hurt to touch?	1	2	3

	Much More	About the Same	Much Less
14. Compared to other people my child's age, the amount of pain my child has is	1	2	3
15. Pain keeps my child from doing the things that s/he wants to do or needs to do	Very True	Somewhat	Not at all
	1	2	3

Understanding

In the past week, was your child:

	A lot	Some	Not at all
16. Bothered that s/he didn't know enough about NF-1?	1	2	3
17. Frustrated about having NF-1?	1	2	3

Sensation

In the past week, has your child:

	Always	Sometimes	Never
18. Had difficulty hearing others when they talk?	1	2	3
Check here if s/he wears a hearing aid _____			
19. Had trouble seeing well?	1	2	3
Check here if s/he wears glasses or contacts _____			
20. Had trouble feeling the things s/he touches?	1	2	3

Symptoms - 1

In the past week, has your child:

	Always	Sometimes	Never
21. Felt sick to his/her stomach?	1	2	3
22. Had a headache?	1	2	3
23. Had a stomachache?	1	2	3
24. Had a hard time breathing?	1	2	3
25. Felt dizzy or like s/he might faint?	1	2	3
26. Felt weak?	1	2	3
27. Felt tired or fatigued?	1	2	3
28. Had a hard time swallowing?	1	2	3
29. Had a hard time keeping his/her balance?	1	2	3

Symptoms - 2

In the past week, has your child:

	Always	Sometimes	Never
30. Had a difficulty tying shoes, using scissors, holding a pencil?	1	2	4
31. Been clumsy?	1	2	4
32. Had a hard time riding a bike, running, or catching a ball?	1	2	4

Psychological and Behavioral - 1

In the past week, has your child:

	Always	Sometimes	Never
33. Felt cranky or irritable?	1	2	4
34. Worried?	1	2	4
35. Felt anxious?	1	2	4
36. Gotten easily frustrated?	1	2	4
37. Gotten in trouble because of his/her behavior at school?	1	2	4
38. Gotten in trouble because of his/her behavior at home?	1	2	4
39. Felt afraid or scared?	1	2	4
40. Felt sad, down, or depressed?	1	2	4
41. Felt angry?	1	2	4
42. Worried about what might happen to him/her?	1	2	4

Psychological and Behavioral - 2

In the past week, has your child:

	Always	Sometimes	Never
43. Felt like crying?	1	2	3
44. Felt lonely?	1	2	3
45. Felt cheerful?	1	2	3
46. Felt confident about him/herself?	1	2	3
47. Enjoyed the things s/he does?	1	2	3
48. Had fun?	1	2	3
49. Felt jittery or restless?	1	2	3
50. Argued?	1	2	3
51. Wanted to be alone?	1	2	3
52. Had mood swings?	1	2	3
53. Not done what his/her parent or teacher asked?	1	2	3
54. Had anxiety or panic attacks?	1	2	3
55. Hit or kicked someone?	1	2	3
56. Heard voices that weren't there?	1	2	3
	Much Worse	Ok	Much Better
57. Compared to other children your child's age, would you say your child's behavior is:	1	2	3

School and Cognition -1

In the past week, has your child:

	Always	Sometimes	Never
58. Missed school because of his/her health?	1	2	3
Check here if school was on vacation _____			
59. Been bothered because s/he missed school?	1	2	3
Check here if your child hasn't missed any school _____			
60. Missed school to go to the doctor or hospital?	1	2	3
61. Had difficulty solving math problems?	1	2	3
62. Had trouble writing papers or reports?	1	2	3
63. Had trouble following or understanding directions?	1	2	3
64. Had difficulty remembering what s/he read?	1	2	3
65. Had trouble reading?	1	2	3
66. Forgotten things?	1	2	3
67. Had trouble keeping up with schoolwork?	1	2	3
68. Had trouble turning schoolwork in on time?	1	2	3

School and Cognition -2

In the past week, has your child:

	Always	Sometimes	Never
69. Had difficulty paying attention and concentrating in class?	1	2	3
70. Had trouble writing neatly?	1	2	3
71. Had a hard time sitting still in class?	1	2	3
72. Had trouble organizing work or things?	1	2	3
73. Had trouble spelling?	1	2	3

In the past week;

	Poor	Ok	Excellent
74. How would you rate your child's ability to do schoolwork?	1	2	3

Social Relations - 1

In the past week, has your child:

	Always	Sometimes	Never
75. Had trouble getting along with other kids?	1	2	3
76. Helped others?	1	2	3
77. Preferred to be alone?	1	2	3
78. Preferred quiet activities?	1	2	3
79. Avoided doing things with other kids?	1	2	3

Social Relations - 2

In the past week, has your child:

	Always	Sometimes	Never
80. Felt bothered because s/he couldn't do the activities they like?	1	2	3
81. Felt like other kids didn't want to do things with them	1	2	3
82. Felt like other kids didn't want to be his/her friend?	1	2	3
	Poor	Ok	Excellent
83. How would you rate your family's ability to get along with each other?	1	2	3
84. How would you rate your child's ability to get along with other kids?	1	2	3

Appearance - 1

In the past week, has your child:

	Always	Sometimes	Never
85. Been teased about how they look?	1	2	3
86. Felt bad about his/her appearance?	1	2	3
87. Worried about their looks?	1	2	3
88. Been teased about size?	1	2	3
89. Avoided doing things with others because of how s/he looks?	1	2	3

Appearance - 2

In the past week, has your child:

	Always	Sometimes	Never
90. Done things to hide part of their body because of how it looks?	1	2	3
91. Noticed people staring at them?	1	2	3
92. Heard strangers make rude comments about them?	1	2	3
93. Worried about other people teasing them?	1	2	3

	Not at all	Somewhat	Very much
94. My child is satisfied with his/her looks	1	2	3

Speech and Language

In the past week, have:

	Always	Sometimes	Never
95. Other people had a hard time understanding your child when s/he talks?	1	2	3
96. My child had a hard time understanding what other people said to them?	1	2	3

Global Ratings

	Poor	OK	Excellent		
97. How would you rate your child's overall quality of life?	1	2	3	4	5

	Very	Somewhat	Not at all		
98. How difficult was it to complete this survey?	1	2	3	4	5
How upsetting was it to complete this survey?	1	2	3	4	5

	Poor	Somewhat	Excellent		
99. How well did the questions in this survey describe your child's quality of life?	1	2	3	4	5
100. What other things would you like to see added that might better describe your child?					

Please Put your Completed Survey in the Stamped, Addressed Envelope and Drop in the Mail! Thank you!

NF-1 Health-Related Quality of Life

Version 2.0

Child Report

Today's Date: _____

Directions:

Children with NF-1 sometimes have special problems. We are interested in **how much of a problem** these might have been for you in the **PAST WEEK**. There are no right or wrong answers! Just circle the number that answers the question. Thanks!

General Health				
1. In general, I would say that my health is:				
1	2	3	4	5
Poor				Excellent
2. Compared to this time last year, I would say my health is:				
1	2	3	4	5
Much Worse				Much Better
3. I get sick more easily than other kids:				
1	2	3	4	5
Yes, Definitely				No, not at all

Appetite and Sleep				
In the past week, have you:				
	Always		Sometimes	Never
4. Had difficulty falling asleep or staying asleep?	1	2	3	4
5. Had bad dreams or nightmares?	1	2	3	4
6. Been less hungry than usual?	1	2	3	4
7. Been more hungry than usual?	1	2	3	4

Who helped you fill out this page? (Circle One) Mother Father No One Other _____

If you received help, please circle the question numbers on this page for which you needed help.

Pain

In the past week, have you:

	Always		Sometimes		Never
8. Hurt a lot?	1	2	3	4	5
9. Had muscle pains or aches?	1	2	3	4	5
10. Had headaches?	1	2	3	4	5
11. Had stomachaches?	1	2	3	4	5
12. Had pain in your bones or joints?	1	2	3	4	5
13. Had neurofibromas or other areas on your body that hurt to touch?	1	2	3	4	5

	Much More		About the Same		Much Less
14. Compared to other people my age, the amount of pain I have is	1	2	3	4	5

	Very True		Somewhat		Not at all
15. Pain keeps me from doing the things that I want to do or need to do	1	2	3	4	5

Who helped you fill out this page? (Circle One) Mother Father No One Other _____
If you received help, please circle the question numbers on this page for which you needed help.

Understanding

In the past week, were you:

16. Bothered that you didn't know enough about NF-1?

1 A lot 2 3 Some 4 5 Not at all

17. Frustrated about having NF-1?

1 A lot 2 3 Some 4 5 Not at all

Sensation

In the past week, have you:

18. Had difficulty hearing others when they talk?

Check here if you wear a hearing aid ____

19. Had trouble seeing well?

Check here if you wear glasses or contacts ____

20. Had trouble feeling the things you touch?

Always		Sometimes		Never
1	2	3	4	5
1	2	3	4	5
1	2	3	4	5

Who helped you fill out this page? (Circle One) Mother Father No One Other

If you received help, please circle the question numbers on this page for which you needed help.

Symptoms - 1

In the past week, have you:

	Always		Sometimes		Never
21. Felt sick to your stomach?	1	2	3	4	5
22. Had a headache?	1	2	3	4	5
23. Had a stomachache?	1	2	3	4	5
24. Had a hard time breathing?	1	2	3	4	5
25. Felt dizzy or like you might faint?	1	2	3	4	5
26. Felt weak?	1	2	3	4	5
27. Felt tired or fatigued?	1	2	3	4	5
28. Had a hard time swallowing?	1	2	3	4	5
29. Had a hard time keeping your balance?	1	2	3	4	5
30. Had a difficulty tying shoes, using scissors, holding a pencil?	1	2	3	4	5
31. Been clumsy?	1	2	3	4	5
32. Had a hard time riding a bike, running, or catching a ball?	1	2	3	4	5

Who helped you fill out this page? (Circle One) Mother Father No One Other _____
 If you received help, please circle the question numbers on this page for which you needed help.

Psychological and Behavioral - 1

In the past week, have you:

	Always		Sometimes		Never
33. Felt cranky or irritable?	1	2	3	4	5
34. Worried?	1	2	3	4	5
35. Felt anxious?	1	2	3	4	5
36. Gotten easily frustrated?	1	2	3	4	5
37. Gotten in trouble because of your behavior at school?	1	2	3	4	5
38. Gotten in trouble because of your behavior at home?	1	2	3	4	5
39. Felt afraid or scared?	1	2	3	4	5
40. Felt sad, down, or depressed?	1	2	3	4	5
41. Felt angry?	1	2	3	4	5
42. Worried about what might happen to you?	1	2	3	4	5
43. Felt like crying?	1	2	3	4	5
44. Felt lonely?	1	2	3	4	5
45. Felt cheerful?	1	2	3	4	5

Who helped you fill out this page? (Circle One) Mother Father No One Other _____
 If you received help, please circle the question numbers on this page for which you needed help.

Psychological and Behavioral - 2

In the past week, have you:

	Always		Sometimes		Never
46. Felt confident about yourself?	1	2	3	4	5
47. Enjoyed the things you do?	1	2	3	4	5
48. Had fun?	1	2	3	4	5
49. Felt jittery or restless?	1	2	3	4	5
50. Argued?	1	2	3	4	5
51. Wanted to be alone?	1	2	3	4	5
52. Had mood swings?	1	2	3	4	5
53. Not done what your parent or teacher asked?	1	2	3	4	5
54. Had anxiety or panic attacks?	1	2	3	4	5
55. Hit or kicked someone?	1	2	3	4	5
56. Heard voices that weren't there?	1	2	3	4	5

57. Compared to other children your age, would you say your behavior is:

1 2 3 4 5
 Much Worse Ok Much Better

Who helped you fill out this page? (Circle One) Mother Father No One Other
 If you received help, please circle the question numbers on this page for which you needed help.

School and Cognition -1

In the past week, have you:

	Always		Sometimes		Never
58. Missed school because of your health? Check here if school was on vacation ____	1	2	3	4	5
59. Been bothered because you missed school? Check here if you haven't missed any school ____	1	2	3	4	5
60. Missed school to go to the doctor or hospital?	1	2	3	4	5
61. Had difficulty solving math problems?	1	2	3	4	5
62. Had trouble writing papers or reports?	1	2	3	4	5
63. Had trouble following or understanding directions?	1	2	3	4	5
64. Had difficulty remembering what you read?	1	2	3	4	5
65. Had trouble reading?	1	2	3	4	5
66. Forgotten things?	1	2	3	4	5
67. Had trouble keeping up with your schoolwork?	1	2	3	4	5

Who helped you fill out this page? (Circle One) Mother Father No One Other _____
If you received help, please circle the question numbers on this page for which you needed help.

School and Cognition -2

In the past week, have you:

	Always		Sometimes		Never
68. Had trouble turning your schoolwork in on time?	1	2	3	4	5
69. Had difficulty paying attention and concentrating in class?	1	2	3	4	5
70. Had trouble writing neatly?	1	2	3	4	5
71. Had a hard time sitting still in class?	1	2	3	4	5
72. Had trouble organizing your work or things?	1	2	3	4	5
73. Had trouble spelling?	1	2	3	4	5

In the past week;

74. How would you rate your ability to do your schoolwork?

1	2	3	4	5
Poor		Ok		Excellent

Who helped you fill out this page? (Circle One) Mother Father No One Other
 If you received help, please circle the question numbers on this page for which you needed help.

Social Relations

In the past week, have you:

	Always		Sometimes		Never
75. Had trouble getting along with other kids?	1	2	3	4	5
76. Helped others?	1	2	3	4	5
77. Preferred to be alone?	1	2	3	4	5
78. Preferred quiet activities?	1	2	3	4	5
79. Avoided doing things with other kids?	1	2	3	4	5
80. Felt bothered because you couldn't do the activities you like?	1	2	3	4	5
81. Felt like other kids didn't want to do things with you?	1	2	3	4	5
82. Felt like other kids didn't want to be your friend?	1	2	3	4	5

	Poor		Ok		Excellent
83. How would you rate your family's ability to get along with each other?	1	2	3	4	5
84. How would you rate your ability to get along with other kids?	1	2	3	4	5

Who helped you fill out this page? (Circle One) Mother Father No One Other _____
 If you received help, please circle the question numbers on this page for which you needed help.

Appearance

In the past week, have you:

	Always 1	2	Sometimes 3	4	Never 5
85. Been teased about how you look?	1	2	3	4	5
86. Felt bad about how you look?	1	2	3	4	5
87. Worried about how you look?	1	2	3	4	5
88. Been teased about your height/weight?	1	2	3	4	5
89. Avoided doing things with others because of how you look?	1	2	3	4	5
90. Done things to hide part of your body because of how it looks?	1	2	3	4	5
91. Noticed people staring at you?	1	2	3	4	5
92. Heard strangers make rude comments about you?	1	2	3	4	5
93. Worried about other people teasing you?	1	2	3	4	5

94. I am satisfied with the way I look	1	2	3	4	5
	Not at all		Somewhat		Very much

Who helped you fill out this page? (Circle One) Mother Father No One Other _____
 If you received help, please circle the question numbers on this page for which you needed help.

Speech and Language

In the past week, have:

95. Other people had a hard time understanding you when you talk?

Always		Sometimes		Never
1	2	3	4	5

96. You had a hard time understanding what other people say to you?

1	2	3	4	5
---	---	---	---	---

Global Ratings

97. How well did the questions in this survey describe your quality of life?

Poor		Somewhat		Excellent
1	2	3	4	5

98. How would you rate your overall quality of life?

Poor		Ok		Excellent
1	2	3	4	5

99. How difficult was it to complete this survey?

Very		Somewhat		Not at all
1	2	3	4	5

100. How upsetting was it to complete this survey?

1	2	3	4	5
---	---	---	---	---

Who helped you fill out this page? (Circle One) Mother Father No One Other
If you received help, please circle the question numbers on this page for which you needed help.

Thank you!

Please Put Your Completed Survey in the Stamped, Addressed Envelope and Drop in the Mail!