

Child and Family Quality of Life, Second Edition (CFQL-2) Manual

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Table of Contents

1.0 Brief Overview	3
2.0 Innovative Features	3
3.0 Development	4
3.1. Conceptual model generation:	4
3.2. Item writing:	5
3.3. Development of the CFQL-2	6
4.0 Validation	6
4.1. Study 1—Validation of the original CFQL	7
4.1.1. Sample:	7
4.1.2. Measures:	8
4.1.3. Findings:	8
4.1.3.1. Factor Structure:	8
4.1.3.2. Reliability:	8
4.1.3.3. Convergent and Discriminant Validity	11
4.2. Study 2—Validation of the revised CFQL-2	13
4.2.1. Sample:	13
4.2.2. Measures:	13
4.2.3. Findings	14
4.2.3.1. Factor Structure	14
4.2.3.2. Reliability and Sensitivity to Change	15
4.2.3.3. Convergent and Discriminant Validity	18
4.3. Study 3— Validation of the CFQL-2: Factor Structure and Regression-Based Norms	20
4.3.1. Sample:	20
4.3.2. Findings:	22
4.3.2.1. Factor Structure	22
4.3.2.2. Measurement Invariance	24
4.3.2.3. Conditional Reliability	25
4.3.2.4. Regression-based Norms	26

5.0 Administration	26
5.1. Response Scales	26
5.2. Rating Frames	26
6.0 Scoring	29
7.0 Interpretation and clinical guidance.	30
7.1. Interpretation for Cross-Sectional Monitoring	30
7.2. Interpretation for General Intervention Recommendations	32
References	34

1.0 Brief Overview

The Child and Family Quality of Life, Second Edition (CFQL-2) is a brief (26-item), open source, freely available informant-report measure specifically developed to comprehensively capture key aspects of psychosocial quality of life (QoL) in families of children with Autism Spectrum Disorder (ASD) and related neurodevelopmental conditions (Frazier et al., 2020). The original CFQL (Markowitz et al., 2016) was designed to measure psychosocial aspects of QoL that are particularly relevant to common problems and needed supports for children and families with ASD and related disorders. Scales were developed to provide information to clinicians that could yield practical recommendations (e.g., family therapy, couples therapy, referral to external support resources, interventions focusing on coping and resilience, etc.). The revised and updated version (CFQL-2) was developed to reduce the administration time and rater burden while maintaining optimal coverage of the key aspects of psychosocial QoL. Importantly, CFQL-2 enables clinicians to track changes over time in multifaceted aspects of psychosocial QoL. CFQL-2 was developed and validated through an iterative and comprehensive process, following gold standard measurement development and validation guidelines. Findings from two large cohorts provide evidence that the CFQL-2 is psychometrically-sound instrument with good reliability of measurement across a continuous range of scores and good evidence of predictive validity. The measure may thus be a useful, reliable, efficient and open-source instrument to effectively capture psychosocial aspects of QoL and characterize and quantify changes in QoL in families of children with ASD or related neurodevelopmental disorders (Frazier et al., 2017).

2.0 Innovative Features

The CFQL-2 has several innovative features that distinguish it from the most commonly used measures in the field, including a balance between brevity and exhaustive domain representation and coverage, robust factor structure and measurement invariance across key parameters including age, sex, and diagnostic status, demonstrated sensitivity to change, state-of-the-art regression-based norms, online system for an easy administration and automatic scoring, and comprehensive set of clinical recommendations.

- Comprehensive domain representation and coverage of key psychosocial aspects of QoL, including child, family, caregiver, financial, social network, partner relationship, and coping QoL not captured by other instruments.
- Careful attention to question wording and responses to ensure that measures are applicable for caregivers and families of diverse backgrounds and socio-economic status that care for children with a wide range of clinical, cognitive, and language

presentations, including non-speaking children, children with severe cognitive or intellectual impairments, and children with severe motor deficits.

- Clear and replicable factor structure derived using state-of-the-art factor analytic approaches.
- Null/very weak associations with race/ ethnicity and measurement invariance
- Use of IRT to demonstrate good reliability (better measurement precision) across key score ranges.
- Regression-based norms accounting for linear and quadratic age effects and sex effects on score distributions.
- Sensitivity to change.
- Standard scores based on large neurotypical normative populations and comparison to clinical populations where relevant.
- Online system for ease of administration, scoring and reporting as well as longitudinal profiling for intervention monitoring.
- Careful attention to convergent and discriminant validity and inclusion of comprehensive validity indicators for each subscale.
- Clear reports with clinical recommendations for diagnostic and treatment contexts.

3.0 Development

The original CFQL was developed through a sequential, iterative process described in detail in relevant publication (CFQL: Markowitz et al., 2015). Following the development and validation of the CFQL, a revised version was derived, validated and published (CFQL-2: Frazier et al., 2020). Below, we describe the measurement development process. At the end of this section, we provide a summary of key changes that were made to the original CFQL in order to derive CFQL-2.

3.1. Conceptual model generation:

Conceptual model of QoL was created based on the conceptual synthesis of existing definitions and models of QoL in the context of children with ASD and their family members and based on the systematic review of the literature and review of existing instruments. In particular, we focused on the following two important aspects of the World Health Organizations of the QoL definition that pertains to the measurement of QoL in ASD/DD populations:

- That multiple levels of the ecological system are relevant to child and family QoL, including the child, their condition/disability, siblings, parents, extended family, and other aspects of the meso- and exo-system; and

- The need to distinguish between broad conceptualizations of QoL (e.g. general happiness) and specific facets (e.g. caregiver or family QoL). More specifically, in the context of ASD and other neurodevelopmental disorders, broad conceptualizations—while potentially useful to track as global outcomes—are less helpful in a clinical context for directing referrals, providing recommendations, or guiding treatment approaches.

The following key content areas were identified: child, family, caregiver, financial, social network, partner relationship, and coping QoL. Noted content areas were then evaluated and rated on a scale of 0=not relevant to 100=highly relevant by neurodevelopmental disability clinician-scientist experts and neurodevelopmental disability caregiver/patient informants. All content areas received a rating of > 70 from both clinician-scientist experts and caregiver/patient informants. An additional concept elicitation process was conducted to explore whether any additional content areas would be identified did not suggest that any aspects of psychosocial QoL were missed. Thus, the described seven psychosocial QoL content areas were retained for the final conceptual model that served as the basis for item generation.

3.2. Item writing:

The research team reviewed existing scales relevant to each domain and content area. Specific scales reviewed included Pediatric Quality of Life Inventory (PedsQL), Child and Family Quality of Life (CFQL), WHO Quality of Life-100 & BREF-ID & Disabilities Module, PROMIS Autism Battery—Lifespan (PAB-L), Quality of Life in Autism Questionnaire (QoLA), Parental Stress Scale (PSS), Parenting Stress Index (PSI). A set of items were written capture each of the seven key content areas. Specific guidelines described below were followed in the process of item generation and writing:

- Items should be as brief as possible to capture the content area,
- That a sufficient number of items were written to ensure that the content area is adequately assessed,
- Ensure as much as possible that items do not probe more than one construct or that endorsement of an item is not a consequence of distinct processes,
- Use plain language (where possible),
Provide examples for less obvious content but avoid excessive wording,
- Provide qualifiers where necessary,
- Ensure adequate coverage with attention to brevity.

3.3. Development of the CFQL-2

The original CFQL was not explicitly designed to measure change. Evaluating change in psychosocial QoL is important for guiding the course of a patient's development or progress during the intervention, identifying the broader family-system effects of therapies, and as an outcome measure in clinical research. Consistent with this notion, clinical trials have begun to include QoL measurements as downstream, ecologically-relevant outcomes. Thus, a revised version of the original CFQL, the CFQL-2, was developed to enable clinicians the ability to track changes over time in multifaceted aspects of psychosocial QoL. Further, the original CFQL included supplemental questions regarding medication use, doctors' visits, child interventions, and additional questions about the child and family setting that extended the administration time of the questionnaire. Thus, in creating the CFQL-2 the goals were to decrease administration time and rater burden and increase sensitivity to change without negatively impacting content validity or reliability.

To accomplish the above noted goals, one or two CFQL questions were removed per subscale, and all of the supplemental questions were eliminated. The CFQL-2 was revised from the original CFQL while maintaining coverage of the prior scales: child, family, caregiver, financial, social network, partner relationship, and coping QoL. Each a priori CFQL-2 subscale is measured by three or four items. The same experienced clinician who developed the original CFQL chose questions for removal from each scale. Eliminated questions had weaker scale-if-item-deleted Cronbach alpha coefficients and/or had lower factor loadings. Items used the same 5-point Likert scales as were used in the original CFQL, indicating the level of agreement with each statement. Differing Likert scale anchors were used to increase the variety of item content, enhance rater engagement, and decrease rater response sets that can artificially inflate internal consistency reliability and inter-correlations between separate constructs. Further, one change item was added to the retained CFQL items for each subscale. The item capturing change was worded similarly for each subscale (e.g. from the CFQL-2 Child QoL subscale: "Over the last month, my child's quality of life has: 0 = Decreased Substantially to 4 = Improved Substantially").

4.0 **Validation**

The CFQL-2 was validated and refined through three independent studies.

- Study 1 focused on the administration and validation of the original CFQL. More specifically, Parents of 212 children suspected of ASD completed the Child and

Family Quality of Life and a number of additional measures prior to a diagnostic evaluation. Factor structure and reliability of the CFQL were explored, and CFQL scores prior to the time of diagnosis in children and families affected by ASD were compared to scores of children and families affected by other neurodevelopmental disorders.

- Study 2 focused on the validation of the revised CFQL-2. More specifically, in Study 2, caregivers of 566 patients presenting to an ASD-specific diagnostic clinic completed the CFQL-2 and other behavioral measurements as part of a diagnostic evaluation. Psychometric properties, including factor structure, internal consistency reliability, reliability across the latent trait, relationships with other clinical measures, and ASD vs. non-ASD group differences were examined for the total score and each subscale. Test-retest reliability and sensitivity to change were evaluated in a separate sleep intervention trial.
- Study 3 focused on validating the CFQL-2 factor structure, examining conditional reliability, and developing regression-based norms. Specifically, informants of 2004 children (see section 4.3) completed the CFQL-2 as part of a larger survey. To examine factor structure, this sample was combined with the sample in Study 2. Only, neurotypical controls were used to estimate regression-based norms.

4.1. Study 1—Validation of the original CFQL

4.1.1. *Sample:*

The sample consisted of consecutive referrals for evaluation of possible ASD to a specialty diagnostic evaluation clinic. Final sample included Parents/guardians of Parents of 212 children (aged 13–86 months). Detailed characteristics of the sample are shown in Table 1.

Table 1. Study 1 Sample Characteristics.

	Non-ASD M (SD)	ASD M (SD)	χ^2/t (<i>p</i>)
N	91	121	
Age (range, months)	3.7 (1.1–6.6)	3.5 (1.2–7.2)	0.85 (0.399)
Male (n, %)	68 (74.7%)	102 (84.3%)	3.00 (0.083)
DSM-IV-TR diagnoses (n, %)			
Any Language Disorder	74 (81.3%)	110 (90.9%)	4.17 (0.041)
Any anxiety disorder	20 (22.0%)	0 (0.0%)	29.36 (<0.001)
Any ADHD	10 (11.0%)	-	
Other diagnosis	21 (23.1%)	2 (1.7%)	24.65 (<0.001)
No diagnosis	4 (4.4%)	-	

Note. ASD= autism spectrum disorder; SD= standard deviation; ADHD: attention-deficit or hyperactivity disorder

4.1.2. Measures:

In addition to the original version of the CFQL, we collected:

- Vineland Adaptive Behavior Scales, second edition (VABS-2): VABS-2 is a parent-report measure used to gain adult perception of the child's communication, daily living, socialization, and motor skills (Sparrow et al., 2005). Total scores are summed and yield norm-referenced standard scores within communication, daily living skills, socialization, and motor skills domains as well as a composite index. Daily Living Skills domain encompasses Personal, Domestic and Community subdomains.
- Child Behavior Checklist (CBCL): CBCL is a parent-report questionnaire completed by the child's parent/guardian to assess a child's behavioral and emotional problems, including internalizing and externalizing behaviors. T-scores from the Total, Internalizing, and Externalizing problems scales were used (Achenbach & Rescorla, 2001).
- Preschool Language Scales, fourth edition (PLS-4): PLS-4 is an individually administered test used to evaluate language. Standard scores for the auditory comprehension, expressive communication, and total language scales were used (Zimmerman et al., 2004).

4.1.3. Findings:

4.1.3.1. Factor Structure:

Exploratory factor analysis suggested that six factor solution had the best fit to the data (comparative fit index [CFI]= .989, Tucker–Lewis index [TLI]= .983, root mean square error of approximation [RMSEA]= .052 [95% CI: .043, .060], standardized root mean residual [SRMR]= .012). Specific factors closely followed the a priori model for item content, with factors easily interpreted as measuring child, family/caregiver, financial, external support, partner relationship, and coping QoL.

4.1.3.2. Reliability:

The Child, Caregiver, External Support, and Coping QoL scales maintained adequate reliability ($>.67$) in the low to moderate score ranges ($\theta = -1.5$ to 0), but reliability was poor in very low ($\theta < -1.5$), high ($\theta = 1-2$), and very high ($\theta > 2$) score ranges. This pattern implies a good ability to discriminate adequate from low

levels of QoL but also suggests that discrimination of low from very low QoL and discrimination of adequate to very high levels require larger score differences. The Family QoL scale had excellent reliability from low to high scores. Reliability only dropped off for very low and very high QoL, implying that this scale is useful for grading level of QoL in a wide range of presentations. The Partner Relationship QoL scale had a similar pattern with very high reliability from low to above average levels of QoL, implying an excellent ability to discriminate well-functioning relationships from those in significant distress. The Financial QoL scale showed excellent reliability from very low to average levels of the latent trait. This implies strong ability to discriminate individuals who are subjectively experiencing distress related to their financial situation versus those who are not. Figure 1 shows IRT response curves.

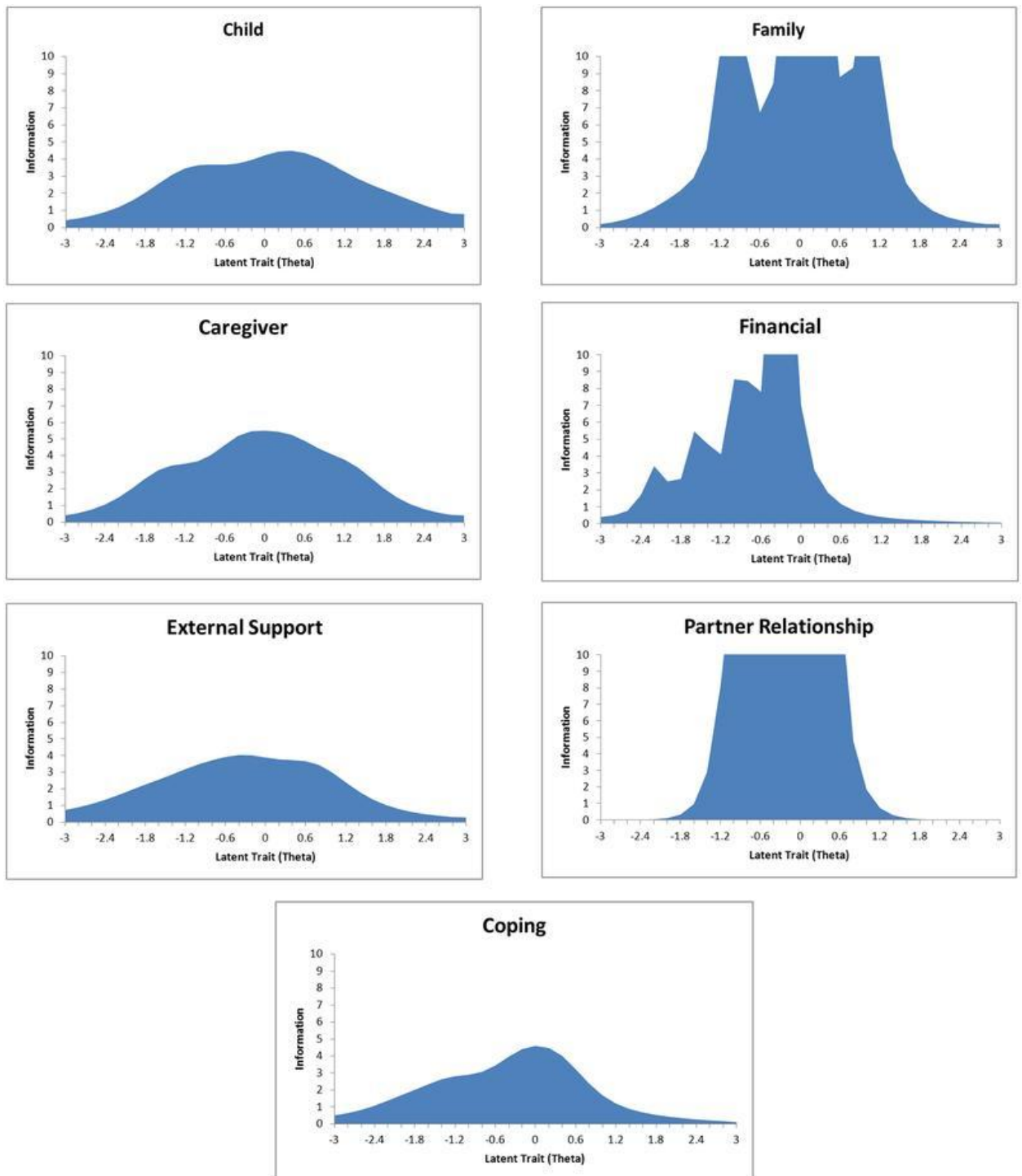


Figure 1. Item information curves for each CFQL scale: child, family, caregiver, financial, external support, partner relationship, and coping.

4.1.3.3. *Convergent and Discriminant Validity*

Low scores on the Child QoL scale were significantly associated with greater autism symptom severity on the Autism Diagnostic Interview-Revised (ADI-R), lower adaptive behavior level, lower expressive and receptive language level, and greater behavior problems. Low scores on the Family, Caregiver, Financial, External Support, and Coping QoL scales were significantly associated with greater behavior problems. However, these scales had no significant relationships with other clinical measures and the Partner Relationship QoL scale was not significantly related to any measure. Table 2 presents a full list of correlations.

Table 2. Convergent and discriminant validity of CFQL scales with autism symptom, behavioral problems, and cognitive measures.

	ADI-R Total	VABS-2 Composite	CBCL Total Problems	PLS-4 Auditory Comprehension	PLS-4 Expressive Communication
Child	-.29*	.22*	-.62*	.20*	.21*
Family	-.17	.14	-.56*	.11	.08
Caregiver	-.06	.07	-.45*	-.01	.04
Financial	-.05	.03	-.26*	.07	.11
External Support	-.07	-.01	-.24*	.08	.06
Partner Relationship	.02	-.02	-.16	-.11	-.13
Coping	-.16	.08	-.31*	.12	.14

Note. * $p < .01$; ADI-R= Autism Diagnostic Interview-Revised; CBCL= Child Behavior Checklist; PLS-4= Preschool Language Scales, fourth edition; VABS-2= Vineland Adaptive Behavior Scales, second edition.

Figure 2 provides summary of the CFQL comparison between children with and without ASD. Children with ASD showed generally lower scores across scales relative to children with non-ASD diagnoses (ASD Diagnosis main effect $F(1,1336)=9.13$, $p=.003$) but the pattern was variable across scales (ASD Diagnosis by CFQL Scale interaction $F(6, 374)=2.24$, $p=.035$). In particular, children with ASD had significantly lower Family QoL scores at the time of diagnosis relative to non-ASD children. There was a trend toward decreased Child QoL and increased Partner Relationship QoL in families containing children with ASD relative to families with non-ASD children ($p<.10$). Including Vineland Communication or Adaptive Composite scores as a covariate did not alter the pattern of findings (smallest ASD Diagnosis by CFQL Scale interaction $F(6, 382)=2.25$, $p=.038$), indicating that this effect was specific to ASD diagnosis and not influenced by the functional level of the child.

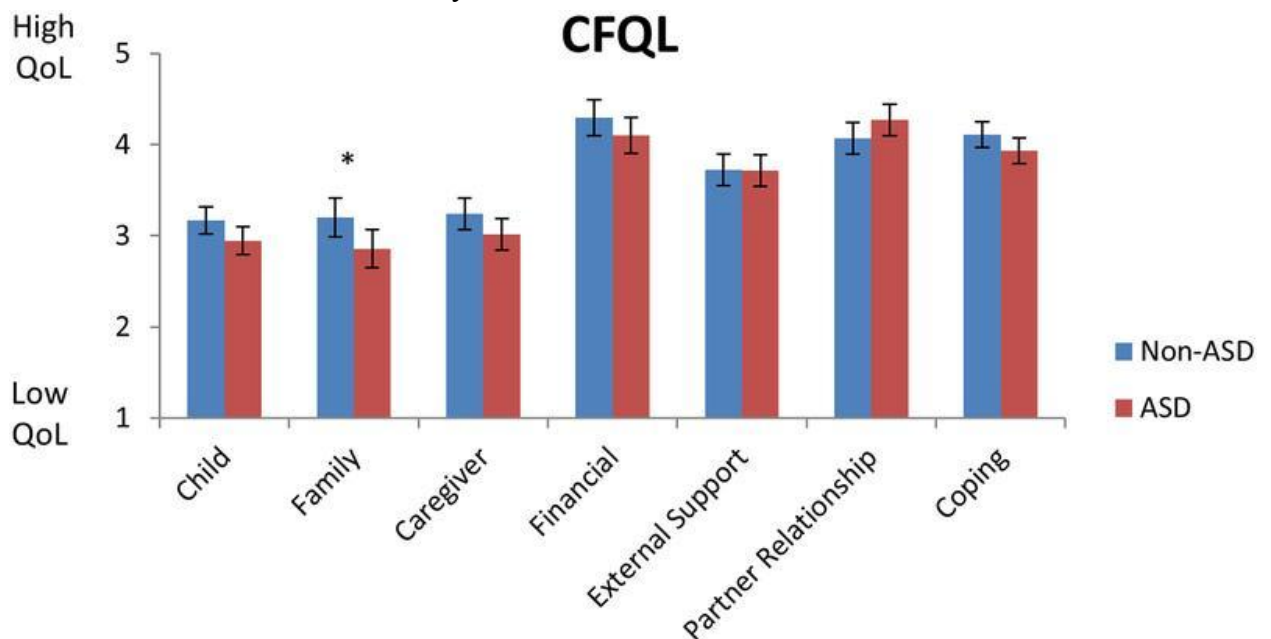


Figure 2. CFQL scores (M $\pm$ 95% CI) across scales in ASD and non-ASD diagnosed children.

Note. *post-hoc Bonferroni-corrected $p<.05$.

4.2. Study 2—Validation of the revised CFQL-2

4.2.1. *Sample:*

The primary sample consisted of patients referred for evaluation of possible ASD to a multi-disciplinary diagnostic evaluation clinic. The final sample included caregivers of 566 patients (aged 9 months-19 years). Detailed characteristics of the sample are shown in Table 3. To assess the test-retest reliability and sensitivity to change, data from 45 ASD-diagnosed children (aged 2.5–12.9 years) enrolled in a treatment study examining the use of a novel mattress technology in improving sleep in children with autism was re-examined (Frazier et al., 2017). Caregivers completed the CFQL-2 at baseline, after week 2, and after week 4.

Table 3. Study 2 Sample Characteristics.

	Non-ASD M (SD)	ASD M (SD)	X ² / t (p)	Cohen's d
N	262	304		
Age in years (SD, range)	7.00 (3.82, 1–18)	5.70 (4.02, 1–19)	3.92 (<.001)	.33
Male (n, %)	190 (72.5%)	247 (81.3%)	6.10 (.014)	.21
White Non-Hispanic (n, %)	170 (65.6%)	186 (63.9%)	0.18 (.674)	.04
DSM-5 Diagnoses				
Any language disorder	161 (61.5%)	294 (96.7%)	110.98 (<.001)	.99
Any anxiety disorder	107 (40.8%)	52 (17.1%)	39.24 (<.001)	.54
Any ADHD	101 (38.5%)	66 (21.7%)	19.18 (<.001)	.37
Other diagnosis	22 (8.4%)	8 (1.4%)	9.32 (.002)	.26
No diagnosis	16 (6.1%)	—	—	

Note. ASD= autism spectrum disorder; SD= standard deviation; ADHD: attention-deficit or hyperactivity disorder

4.2.2. *Measures:*

In addition to the CFQL-2, we collected:

- Child Behavior Checklist (CBCL): CBCL is a parent-report questionnaire completed by the child's parent/guardian to assess a child's behavioral and emotional problems, including internalizing and externalizing behaviors (Achenbach & Rescorla, 2001).

T-scores from the Total, Internalizing, and Externalizing problems scales were used.

- Autism Diagnostic Observation Schedule – Second Edition (ADOS-2): ADOS-2 is a semi-structured, interactive measure designed to assess aspects of communication, social reciprocal interaction, play, and restricted/repetitive/stereotyped behaviors. Total calibrated severity scores for modules 1–3 were included in analyses, as calibrated severity scores for module 4 and the toddler module were not available at the time of this data collection.
- Social Responsiveness Scale – Second Edition (SRS-2): SRS-2 is a 65-item quantitative assessment of the severity of autism traits (Constantino & Gruber, 2012). The total sex-adjusted T-score was included in analyses
- Adaptive Behavior Assessment System-II (ABAS-2): ABAS-2 is a parent-completed questionnaire that assesses adaptive skills, and provides composite scores for three general areas of adaptive behavior (conceptual, social, and practical) (Oakland & Harrison, 2008). Total ABAS-2 standardized composite, Conceptual, Social, and Practical sub-scores were included in analyses.
- Mullen Scales of Early Learning (MSEL): MSEL was administered to a subset of young children (age<6). The visual reception subtest that estimates non-verbal ability was used (Mullen, 1995).
- Clinical Evaluation of Language Fundamentals– Fifth Edition (CELF 5) or Preschool Second Edition (CELF-2): CELF-2/CELF-5 were used to estimate language ability (Wiig et al., 2013; Wiig et al., 2004). Test scores were standardized using available norms from all measures and converted to a common standard score metric ($M = 100$, $SD = 15$) prior to analysis.

4.2.3. Findings

4.2.3.1. Factor Structure

Exploratory factor analyses identified 6- to 7-factor solutions as plausible. A priori scales tended to comprise separate factors, although consistent with the original CFQL, family and caregiver QoL items tended to load together. Confirmatory factor analysis indicated that the best fitting models were the 8-factor model, which separated a priori scales and specified a distinct change scale with cross-loadings on the newly added change items, and

the 7-factor model (model 7b), which was identical to model 8 except that items evaluating family and caregiver QoL loaded on one factor. These results indicate that family and caregiver items can be collapsed into a single scale in most situations. However, given previous analyses of the a priori scales indicating that family QoL - but not caregiver QoL - is reduced in ASD, subsequent analyses evaluated the a priori-scored scales.

4.2.3.2. *Reliability and Sensitivity to Change*

Internal consistency reliability and average corrected item-total correlations were good, especially considering scale length (Table 4).

Table 4. Internal Consistency Reliability, Average Item-Total Correlation, and Test-Retest Reliability for All CFQL-2 Scales and the Total Score.

QoL Subscale	Internal Consistency	Average Corrected Item-Total r	Test-Retest		
	Cronbach's α		Week 0 to 2	Week 2 to 4	Week 0 to 4
			n = 49	n = 32	n = 31
Child	.57	.37	.58	.52	.78
Family	.81	.67	.50	.45	.77
Caregiver	.69	.50	.73	.63	.63
Financial	.80	.73	.57	.81	.63
Social Network	.73	.54	.87	.77	.80
Partner Relationship	.84	.71	.66	.60	.60
Coping	.64	.47	.61	.15	.62
Family Plus Caregiver	.86	.63	.65	.50	.71
Change	.73	.46	.39	-.16	-.30
Total	.89	.48	.71	.58	.71

Note. All test-retest reliability Pearson Correlation Coefficient $>.35$ were significant ($p < .01$). For internal consistency reliability and average item-total correlation analyses, sample sizes vary due to missing data on individual items. For these analyses, only cases with complete data on all items for the sub-scale are included in the analysis (listwise deletion).

Overall, across the CFQL-2 total and sub-scales, item response theory information curves indicated adequate to excellent reliability in the ranges of the latent trait important for discriminating impaired QoL from average QoL ($\theta = -2$ to $\theta = 0$). The Child QoL subscale maintained adequate reliability ($> .60$) from low to high scores. The Social Network, Partner Relationship, and Financial QoL subscales maintained good to excellent reliability ($> .80$) in the low to average score ranges ($-2.0 < \theta < 0$), but reliability dropped precipitously in the high and very high score ranges ($\theta > 0$). These results imply that these subscales had a strong ability to discriminate individuals who are subjectively experiencing reduced QoL from those who are not experiencing QoL reductions; however, the scales were unable to distinguish average QoL from high or very high QoL. The Coping QoL subscale exhibited a similar pattern but was slightly better able to distinguish average from high levels of QoL. Figure 3 shows IRT response curves.

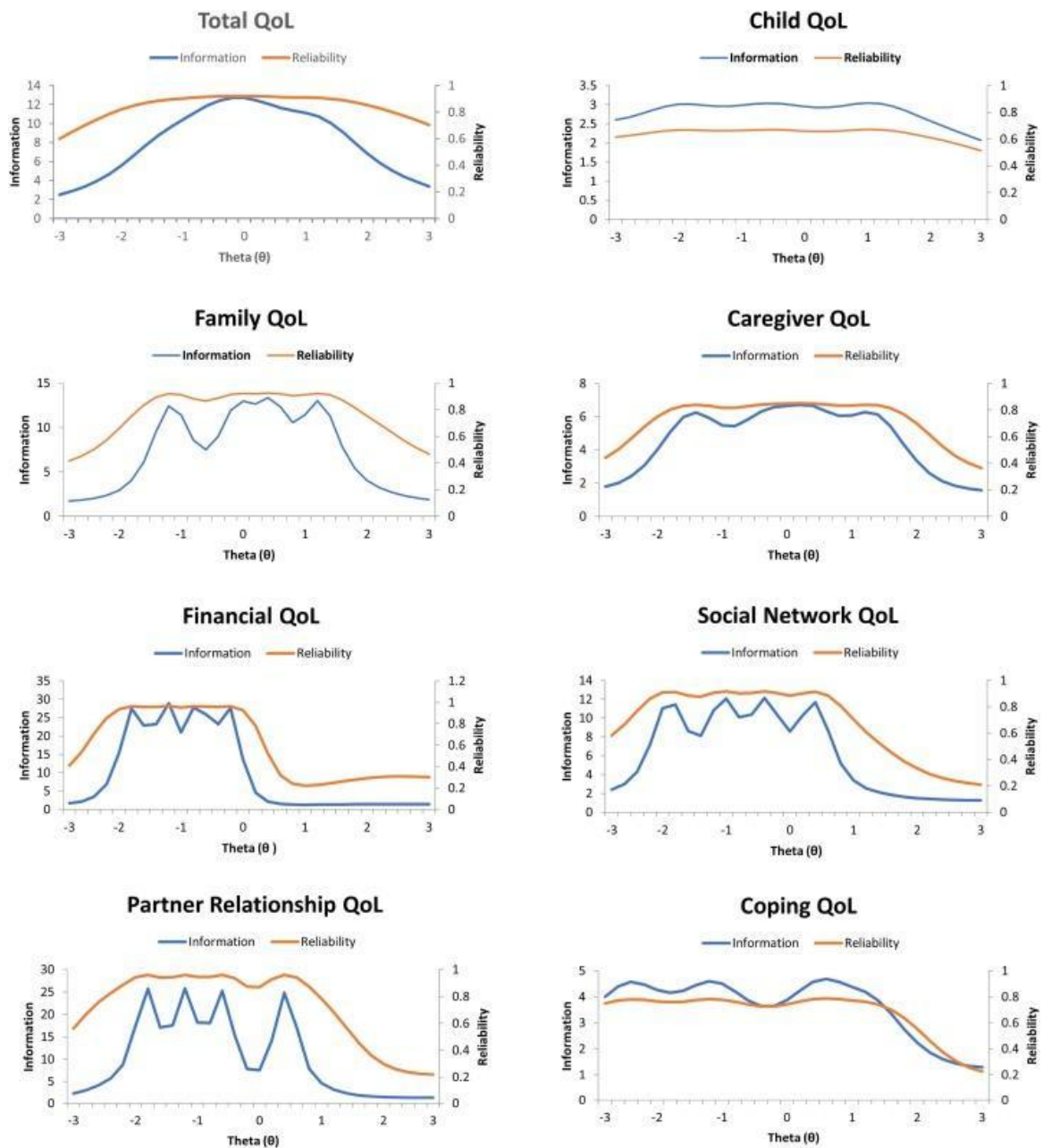


Figure 3. Item information curves for CFQL-2 total and subscales.

Using the intervention study data, CFQL-2 total and subscale scores showed good test-retest reliability with the only exception being a non-significant coefficient for coping from week 2 (cross-over) to week 4 (end of study). These values should be considered lower-bound estimates of test-retest reliability as all

children were receiving an efficacious intervention. As anticipated, change subscale scores showed little stability across weeks. Sensitivity to change was stronger for the CFQL-2 change score ($F(1,34) = 7.59$, $p = .009$, Cohen's $d = .94$, disattenuated $r = .51$) than for the CFQL total score ($F(130) = 5.33$, $p = .028$, Cohen's $d = .84$, disattenuated $r = .40$). The difference in CFQL-2 change subscale scores between active and inactive treatment conditions was significantly positively correlated with actigraphy-derived changes in sleep efficiency across these conditions ($r = .38$, $p = .045$), implying that at least a portion of the change in QoL assessed by these scores represents actual change in QoL.

4.2.3.3. *Convergent and Discriminant Validity*

Consistent with our expectation, higher autism trait severity on the SRS-2 was strongly associated with lower QoL for all subscales ($p < .001$) except Partner Relationship. Better adaptive function was also associated with higher QoL for most scales ($p < .01$), except for the partner relationship, coping, and the change subscales. Higher receptive and expressive language scores were significantly, but weakly, associated with worse QoL across measures, and non-verbal ability was not associated with QoL. Table 5 presents a full list of correlations.

Table 5. Relationships between CFQL-2 Subscales and Clinical Measures.

QoL Subscale(s)	ADOS-2 Calibrated Severity	SRS-2 total	ABAS-2 Composite	Receptive Language	Expressive Language	Non-Verbal Ability
Child	.17	-.57	.33	-.20	-.27	-.08
Family	.04	-.46	.27	-.07	-.13	.03
Caregiver	.06	-.38	.21	-.11	-.18	.05
Financial	.02	-.23	.18	.06	.02	.04
Social Network	.09	-.27	.19	-.02	-.05	.06
Partner Relationship	.12	-.09	.06	-.10	-.13	-.05
Coping	.05	-.28	.08	-.11	-.14	.06
Change	.09	-.23	.08	-.16	-.23	.02

QoL Subscale(s)	ADOS-2 Calibrated Severity	SRS-2 total	ABAS-2 Composite	Receptive Language	Expressive Language	Non-Verbal Ability
Total	.12	-.44	.26	-.11	-.19	.02

Note. Bold indicates correlation is significant at $p < .001$. ADOS-2: Autism Diagnostic Observation Schedule (2nd ed.); SRS-2: Social Responsiveness Scale (2nd ed.); ABAS-2: Adaptive Behavior Assessment System-II; SS: standard score; CFQL-2: Child and Family Quality of Life Scale-2.

Figure 4 provides a summary of the CFQL-2 comparison between children with and without ASD. Family QoL was significantly lower in ASD-affected families than those with non-ASD patients ($F(1,553) = 7.15$, $p = .009$; Cohen's $d = .23$) (Fig. 2), even after accounting for internalizing and externalizing behaviors. There was a non-significant trend toward lower Financial QoL in ASD-affected families ($F(1,553) = 3.37$, $p = .067$; Cohen's $d = .16$).

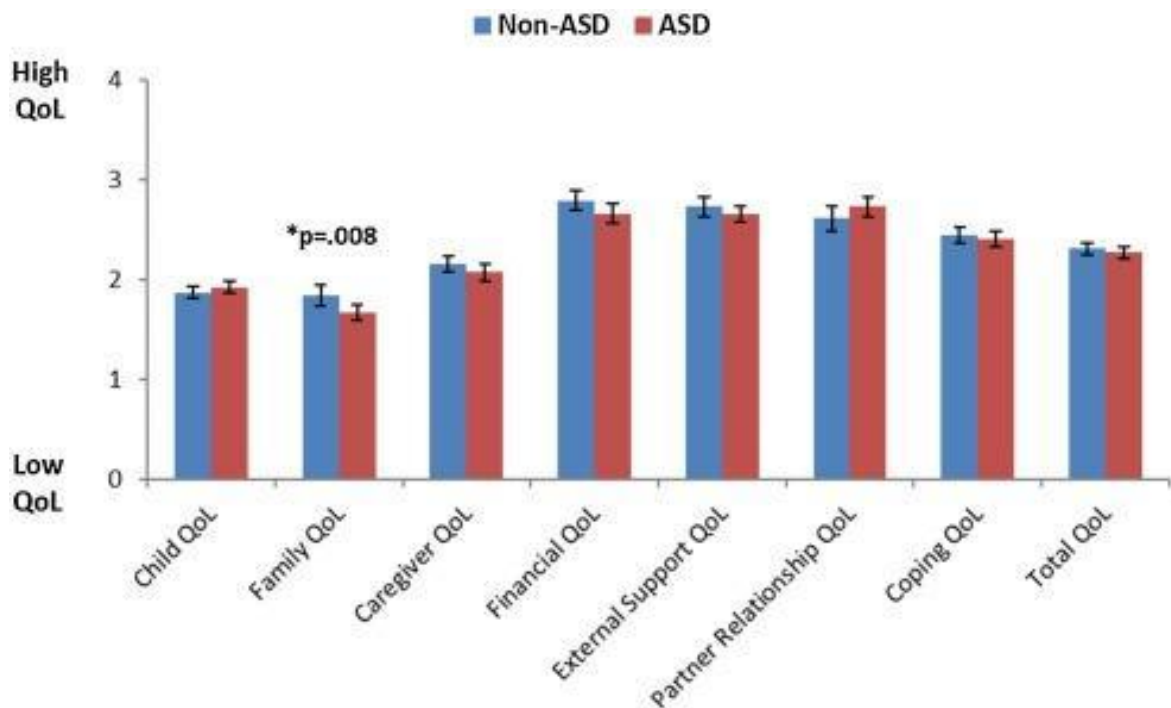


Figure 4. CFQL scores (M $\pm$ 95% CI) across scales in ASD and non-ASD diagnosed children.

4.3. Study 3— Validation of the CFQL-2: Factor Structure and Regression-Based

Norms

4.3.1. Sample:

Informants were recruited using the Prolific online data collection service (<https://prolific.co/>). The final sample was comprised of 2,004 children and adolescents (ages 2-17). Detailed characteristics of the sample are shown in Table 3.

Table 6. Study 3 Sample Characteristics.

	ASD n (%)	DD n (%)	NT n (%)	X ² / F (p)
N	169	541	1294	
Informant Age				43.1 (<.001)
18 to 24	4 (2%)	4 (1%)	43 (3%)	
25 to 34	43 (25%)	124 (23%)	416 (32%)	
35 to 44	70 (41%)	229 (42%)	531 (41%)	
45 to 54	42 (25%)	137 (25%)	230 (18%)	
55 to 64	9 (5%)	42 (8%)	59 (5%)	
65 to 74	1 (0%)	5 (1%)	13 (1%)	
75 or older	0 (0%)	0 (0%)	2 (1%)	
Informant Sex				39.9 (<.001)
Male	37 (22%)	135 (25%)	445 (34%)	
Female	129 (76%)	406 (75%)	847 (66%)	
Did not report	3 (2%)	0 (0%)	2 (1%)	
Informant Relationship Status				37.8 (<.001)
Married	95 (56%)	358 (66%)	953 (74%)	
Single, never married	19 (11%)	51 (9%)	91 (7%)	
Divorced, separated, widowed	37 (22%)	71 (13%)	118 (9%)	
Single, cohabitating	18 (11%)	61 (11%)	128 (10%)	
Household Income (US \$)				40.9 (<.001)
<\$25,000	27 (16%)	65 (12%)	103 (8%)	
\$25,000-\$34,999	19 (11%)	58 (11%)	116 (9%)	
\$35,000-\$49,999	29 (17%)	64 (12%)	137 (11%)	
\$50,000-\$74,999	34 (20%)	122 (23%)	278 (21%)	
\$75,000-\$99,999	26 (15%)	96 (18%)	218 (17%)	
\$100,000-\$149,999	18 (11%)	88 (16%)	272 (21%)	
\$150,000-\$199,999	9 (5%)	27 (5%)	88 (7%)	
\$200,000+	5 (3%)	18 (3%)	68 (5%)	
Did not report	2 (1%)	3 (1%)	14 (1%)	
Child Age (M, sd)	10.5 (4.8)	11.4 (4.6)	8.5 (4.7)	77.4 (<.001)
Child Sex				54.1 (<.001)
Male	128 (76%)	299 (55%)	617 (48%)	
Female	41 (24%)	241 (44%)	674 (52%)	
Intersex	0 (0%)	1 (1%)	0 (0%)	
Did not report	0 (0%)	0 (0%)	3 (<1%)	
Child Race / Ethnicity				

White / Caucasian	138 (82%)	450 (83%)	1065 (82%)	0.3 (.865)
Black / AA	18 (11%)	52 (10%)	118 (9%)	0.5 (.795)
Middle Eastern or North African	1 (1%)	4 (1%)	2 (<1%)	4.1 (.131)
East Asian	3 (2%)	8 (2%)	45 (4%)	6.3 (.042)
South Asian	2 (1%)	1 (<1%)	21 (2%)	6.7 (.036)
Native American / Alaskan Native	4 (2%)	14 (3%)	18 (1%)	3.4 (.179)
Native Hawaiian / Pacific Islander	1 (1%)	4 (1%)	6 (1%)	0.5 (.764)
Multi-racial	18 (11%)	50 (9%)	104 (8%)	1.7 (.425)
Hispanic	22 (13%)	74 (14%)	139 (11%)	6.9 (.141)
Unknown	0 (0%)	2 (<1%)	3 (<1%)	0.8 (.686)
Did not report	1 (1%)	1 (<1%)	11 (1%)	2.6 (.269)
Autism Severity Level (informant-rated)				
Mild	82 (48%)	-	-	
Moderate	74 (44%)	-	-	
Severe	13 (8%)	-	-	
Cognitive Level (informant-estimated)				347.5 (<.001)
Very high or above (120+)	20 (12%)	59 (11%)	131 (10%)	
High Average (110-119)	39 (23%)	188 (35%)	579 (45%)	
Average (90-109)	51 (30%)	216 (40%)	559 (43%)	
Below average (80-89)	16 (10%)	34 (6%)	13 (1%)	
Borderline impairment (70-79)	7 (4%)	23 (4%)	12 (1%)	
Mild impairment (55-69)	14 (8%)	12 (2%)	0 (0%)	
Moderate impairment (40-54)	17 (10%)	7 (1%)	0 (0%)	
Severe impairment (21 to 39)	4 (2%)	1 (<1%)	0 (0%)	
Profound impairment (<20)	1 (1%)	1 (<1%)	0 (0%)	
Non-ASD Diagnoses (n, %)				
ID/GDD	17 (10%)	23 (4%)	-	8.2 (.004)
Speech/language disorder	31 (18%)	98 (18%)	-	<0.1 (.946)
ADHD	53 (31%)	262 (48%)	-	15.2 (<.001)
ODD/CD	13 (8%)	46 (9%)	-	0.1 (.739)
Anxiety disorder	36 (21%)	192 (36%)	-	11.9 (<.001)
Specific learning disorder	9 (5%)	62 (12%)	-	5.4 (.020)
Motor / coordination disorder	9 (5%)	19 (4%)	-	1.1 (.290)
Depressive disorder	17 (10%)	83 (15%)	-	3.0 (.085)
Bipolar disorder / mania	4 (2%)	7 (1%)	-	1.0 (.324)
Obsessive compulsive disorder	10 (6%)	16 (3%)	-	3.2 (.074)
Tic disorder	4 (2%)	5 (1%)	-	2.1 (.143)
Feeding / eating disorder	7 (4%)	21 (4%)	-	<0.1 (.879)

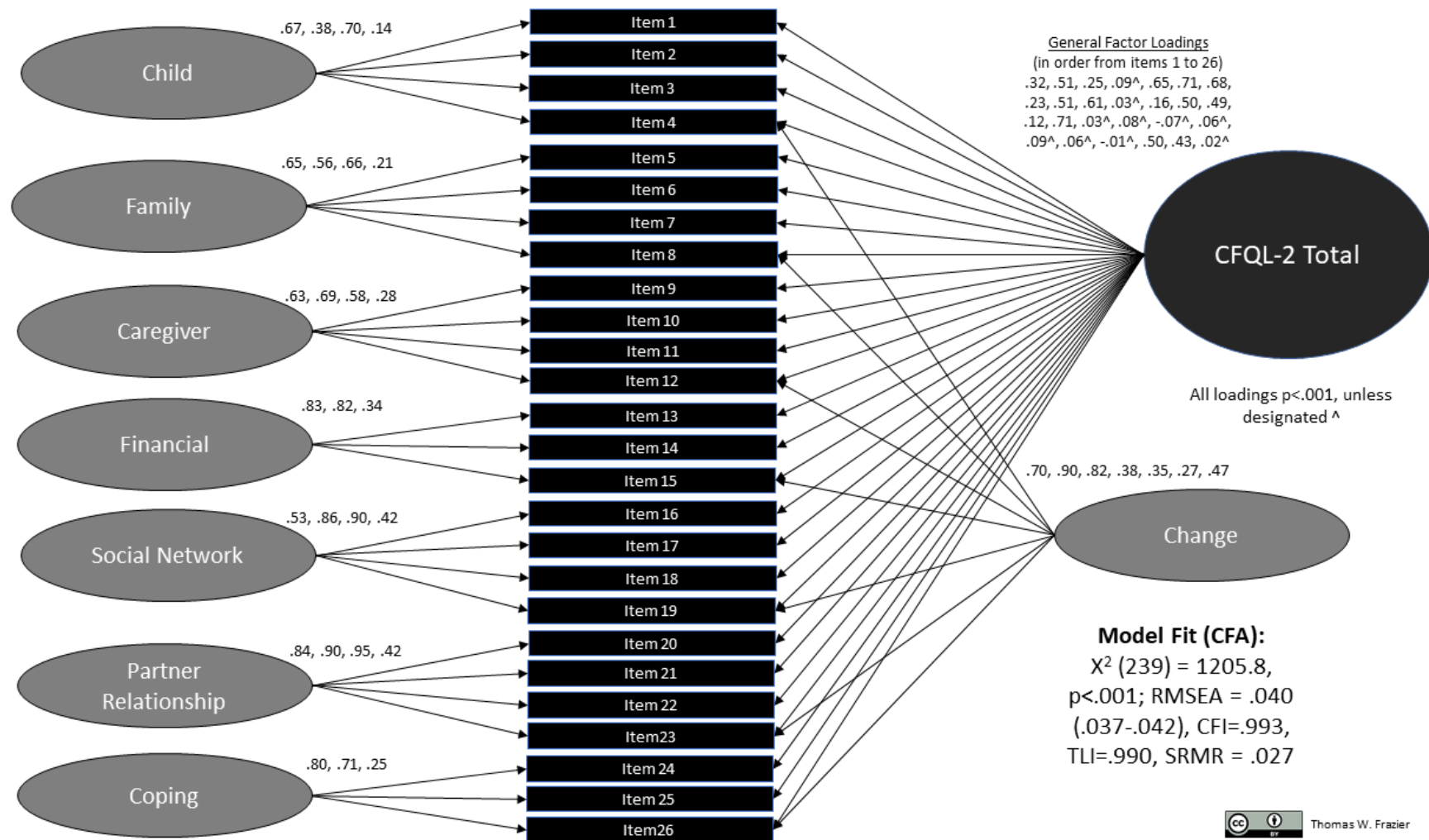
Note. NT=neurotypical controls, DD=non-ASD developmental disability, ASD=autism spectrum disorder. ID/GDD=Intellectual disability/global developmental delay, ADHD=Attention-Deficit/Hyperactivity disorder; ODD/CD=oppositional defiant disorder/conduct disorder. Non-ASD diagnoses do not sum to 100% because children could be diagnosed with more than one condition.

4.3.2. Findings:

4.3.2.1. **Factor Structure**

Exploratory Structural Equation Models (ESEMs) and confirmatory factor models (CFAs) estimated 7 and 8 factor solutions, with and without a general bifactor, representing slight deviations from the a priori model estimated – consistent with prior factor analytic results from Studies 1 and 2. Results in the combined sample (N=2570) indicated that the 8-factor model with a specific change subscale and a general QoL bifactor fit best. Specifically, while the ESEM version of this model fit slightly better, the CFA version still had very good fit [fit indices: CFI=.993, TLI=.990, RMSEA=.040 [95% CI: .037, .042], SRMR=.027] (Figure 5).

Figure 5. Best fitting factor model in the combined sample.



4.3.2.2. *Measurement Invariance*

The CFA model described above could not be directly examined for measurement invariance due to problems with estimation when including a general bifactor. Therefore, a correlated factor model version was evaluated for measurement invariance following standard conventions (Putnick & Bornstein, 2016). The correlated factor model showed evidence of strong (scalar) measurement invariance of factor loadings and thresholds across sex, age, race, and ethnicity.

Table 7. Measurement invariance analyses for the CFQL-2 correlated factor model across sex, age, race, and ethnicity.

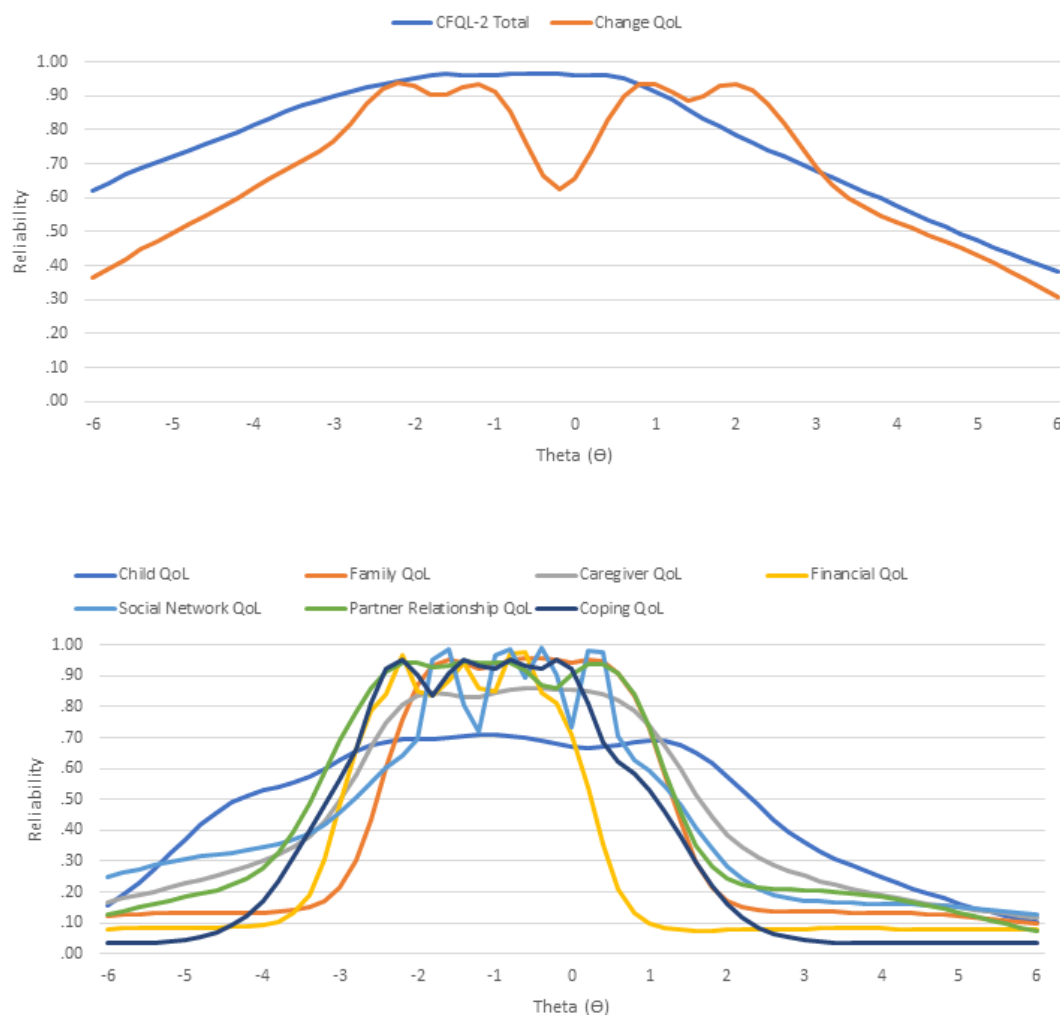
Sex (M, F)												
<i>Fit</i>							<i>Difference Testing</i>					
Model	Par	X ²	DF	RMSEA	CFI	TLI	X ²	DF	p	ΔRMSEA A	ΔCFI	ΔTLI
Configural	438	14336.5	762	.144	.901	.883	-	-	-	-	-	-
Metric	402	14032.5	798	.139	.903	.891	55.5	36	.020	-.005	.002	.008
Scalar	266	13609.3	934	.126	.907	.911	735.0	136	<.001	-.013	.004	.020
Age (2-4, 5-11, 12-17)												
<i>Fit</i>							<i>Difference Testing</i>					
Model	Par	X ²	DF	RMSEA	CFI	TLI	X ²	DF	P	ΔRMSEA A	ΔCFI	ΔTLI
Configural	292	14002.1	508	.144	.892	.873	-	-	-	-	-	-
Metric	274	13784.9	526	.140	.894	.879	25	18	.125	-.004	.002	.006
Scalar	206	12938.4	594	.127	.901	.900	184.9	68	<.001	-.013	.007	.021
Race (Caucasian, other races)												
<i>Fit</i>							<i>Difference Testing</i>					
Model	Par	X ²	DF	RMSEA	CFI	TLI	X ²	DF	P	ΔRMSEA A	ΔCFI	ΔTLI
Configural	292	14944.4	508	.149	.890	.870	-	-	-	-	-	-
Metric	274	14626.3	526	.144	.892	.877	29.6	18	.041	-.005	.002	.007
Scalar	206	13668.4	594	.131	.900	.899	165.8	68	<.001	-.013	.008	.022
Ethnicity (Hispanic, non-Hispanic)												
<i>Fit</i>							<i>Difference Testing</i>					
Model	Par	X ²	DF	RMSEA	CFI	TLI	X ²	DF	P	ΔRMSEA A	ΔCFI	ΔTLI
Configural	292	13579.6	508	.142	.900	.882	-	-	-	-	-	-
Metric	274	13072.8	526	.136	.904	.890	28.1	18	.060	-.006	.004	.008
Scalar	206	12115.6	594	.123	.912	.911	111.3	68	.001	-.013	.008	.021

Notes. CFI, comparative fit index; TLI, Tucker-Lewis index; RMSEA, root mean square error of approximation.

4.3.2.3. *Conditional Reliability*

Conditional reliability estimates indicated at least adequate reliability ($\geq .70$) for the total CFQL-2 scale from extremely low ($\theta \sim -5.0$) to very high ($\theta \sim +2.8$) scores. Adequate or better reliability ($\geq .70$) was present for the change subscale for most of the range from very low ($\theta \sim -3.4$) to very high scores ($\theta \sim +3.2$) (Figure 6 - top). Subscale conditional reliability tended to be adequate or better from very low ($\theta \sim -2.2$) to high ($\theta \sim +1.0$) scores, with some idiosyncratic patterns across subscales.

Figure 6. Conditional reliability for the CFQL-2 total and change scales (top) and subscales (bottom).



4.3.2.4. *Regression-based Norms*

Regression-based norms were computed for the total CFQL-2 score and each subscale using all neurotypical cases from Sample 3 (n=1294).

5.0 Administration

5.1. Response Scales

The full CFQL-2 instrument is presented below. Items used the same 5-point Likert scales used in the original CFQL, indicating the level of agreement with each statement. Differing Likert scale anchors were used to increase the variety of item content, enhance rater engagement, and decrease rater response sets that can artificially inflate internal consistency reliability and inter-correlations between separate constructs.

5.2. Rating Frames

Questionnaire instructions ask participants to use past month as a rating frame to allow aggregation across a longer time period and avoid short-term fluctuations in QoL overly impacting ratings.

Child and Family Quality of Life – Second Edition (CFQL- 2)

INSTRUCTIONS: In order to better understand you, the child you are rating, and your family’s quality of life, please read each question carefully and *circle one* of the provided answers. Circle only one response for each item. Please mark an answer for each item, even if you are not completely sure of your answer. There are no correct or incorrect answers. Your responses will be treated confidentially.

Some questions are framed negatively and some positively. When a question refers to a child’s “difficulties” this could refer to a specific developmental problem (if present), a set of symptoms or behavioral issues, or simply to everyday life hassles and problems. Please read all questions carefully before responding to be sure you are answering the question accurately.

Child QoL

Please rate (circle) the following questions based upon observations of your child during the past month. The questions are not intended to capture your child’s symptoms but rather his/her quality of life.

1.	My child deals with daily life hassles and daily activities well.	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
2.	My child requires reminders to complete everyday tasks that are appropriate.	Never	Rarely	Sometimes	Often	Always
3.	My child appears happy and content.	Never	Rarely	Sometimes	Often	Always
4.	Over the last month, my child’s quality of life has:	Improved Substantially	Improved Slightly	Same	Decreased Slightly	Decreased Substantially

Family QoL

5.	My child’s difficulties have added stress to our home life.	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
6.	My child’s difficulties limit our family from social activities.	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
7.	My child’s problems make it difficult for our family to relax.	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
8.	Over the last month, our family’s quality of life has:	Improved Substantially	Improved Slightly	Same	Decreased Slightly	Decreased Substantially

Caregiver QoL

9.	I feel tired and without energy as a result of caring for my child.	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
10.	I am frustrated that my child's behavior is unmanageable.	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
11.	I think I manage stress related to caring for my child very well.	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
12.	Over the last month, my quality of life has:	Improved Substantially	Improved Slightly	Same	Decreased Slightly	Decreased Substantially

Financial QoL

13.	My family's financial situation has been difficult as a result of my child's problems.	Not at All	A little	Somewhat	Quite a bit	Very Much
14.	The money available for "extras" has been reduced as a result of my child's problems.	Not at All	A little	Somewhat	Quite a bit	Very Much
15.	Over the last month, our financial quality of life has:	Improved Substantially	Improved Slightly	Same	Decreased Slightly	Decreased Substantially

Social Network QoL

Please rate each of the following statements in relation to your social network and the external support you have received in caring for your child and your family over the past month. Note. social network refers to your (caregiver's) parents, siblings, cousins, friends, etc.

16.	I think my friends and family members avoid me because of my child's behaviors.	Not at All	A little	Somewhat	Quite a bit	Very Much
17.	I have a strong support system and others I can consistently rely on.	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
18.	I feel alone, isolated and without friends or family to rely upon.	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
19.	Over the last month, my external support has:	Improved Substantially	Improved Slightly	Same	Decreased Slightly	Decreased Substantially

Partner Relationship QoL

I have a significant other/spouse/partner (please circle one). Yes No

If you answered no, please move onto the next section “Coping”

If yes, please indicate the relationship between your spouse/partner and your child.

Biological Parent Non-Biological Parent Other
(specify) _____

If you answered yes, please rate each of the following statements in relation to your romantic relationship over the past month.

20.	My relationship with my spouse/partner is positive.	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
21.	My spouse/partner and I see eye-to-eye on how to best care for my child.	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
22.	My spouse/partner and I communicate well about our child and family’s needs.	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
23.	Over the last month, my relationship with my spouse/partner has:	Improved Substantially	Improved Slightly	Same	Decreased Slightly	Decreased Substantially

Coping QoL

Note. coping with your child’s difficulties may refer to their specific problems or may simply be the ups and downs of their daily experience.

24.	I find it difficult to cope with my child’s difficulties.	Never	Rarely	Sometimes	Often	Always
25.	I feel angry about my child’s condition.	Never	Rarely	Sometimes	Often	Always
26.	Over the last month, my ability to cope with my child’s difficulties has:	Improved Substantially	Improved Slightly	Same	Decreased Slightly	Decreased Substantially

6.0 Scoring

CFQL-2 items use one of 3 different Likert scales – Agree/Disagree (1=Strongly Disagree, 2=Disagree, 3=Neutral, 4=Agree, and 5=Strongly Agree), Frequency (1=Never, 2=Rarely, 3=Sometimes, 4=Often, 5=Always), or Improvement (1=Improved Substantially, 2=Improved Slightly, 3=Same, 4=Decreased Slightly, 5=Decreased Substantially). For each item, scores are transferred using the 1-5 scale to the excel spreadsheet (see attached). These scores are then recoded with negative scores transformed and summed to produce scale scores for each of the specific subdomains (Table 8).

Table 8. Subscale content

Scale	Items
Total	Sum of all items
Child QoL	Sum of items 1-4
Family QoL	Sum of items 5-8
Caregiver QoL	Sum of items 9-12
Financial QoL	Sum of items 13-15
Social Network QoL	Sum of items 16-19
Partner Relationship QoL	Sum of items 20-23
Coping QoL	Sum of items 24-26

7.0 Interpretation and clinical guidance.

CFQL-2 automatic scoring system provides a separate set of guidelines and recommendations for cross-sectional monitoring, general intervention approach, and treatment target selection. These recommendations are generated through the evidence-based scoring algorithms built into the online administration and scoring platform and are produced as a report. For each individual assessment, the interpretation process involves the following steps:

1. Checking the validity of the scores;
2. Examination and interpretation of the total score;
3. Examination and interpretation of subscale scores; and
4. Identifying specific actions and/or recommendations.

Through each of the described steps, clinician is assisted/guided by the specific recommendations outputted by the automatic scoring system. Abbreviated examples of the cross-sectional monitoring and general intervention approach interpretation and guidelines are provided below.

7.1. Interpretation for Cross-Sectional Monitoring

The table below presents results for a hypothetical 7-year-old male with very low QoL levels.

Scales	Item Average	Content Description	SS	90% CI (+/-)	Percentile (%)	Normative Description
<i>Total QoL</i>	1.0	Low	3	8	<0.01	Very Low QoL
<i>Child QoL</i>	1.0	Low	25	16	<0.01	Very Low QoL
<i>Family QoL</i>	1.0	Low	37	11	<0.01	Very Low QoL
<i>Caregiver QoL</i>	1.0	Low	46	14	<0.01	Very Low QoL
<i>Financial QoL</i>	1.0	Low	7	11	<0.01	Very Low QoL
<i>Social Network QoL</i>	1.0	Low	24	13	<0.01	Very Low QoL
<i>Partner Relationship QoL</i>	1.0	Low	39	10	<0.01	Very Low QoL
<i>Coping QoL</i>	1.0	Low	22	15	<0.01	Very Low QoL
					<0.01	Substantially Decreased
<i>CFQL-2 Change Scale</i>	1.0	decreased	23	13		QoL

- The total quality of life score indicates Very Low QoL, likely extending across multiple aspects of life satisfaction, with the score falling below the 0.1 percentile. Please check subscale scores to identify more specific patterns of quality of life.
- The child quality of life subscale score indicates Very Low QoL for the child relative to neurotypical children, with the score falling below the 0.1 percentile. Please check against other clinical observations.
- The family quality of life subscale score indicates Very Low QoL for the family due to the child's difficulties, with the score falling below the 0.1 percentile. Please check against other clinical observations.
- The caregiver quality of life subscale score indicates Very Low QoL for the caregiver due to the child's difficulties, with the score falling below the 0.1 percentile. Please check against other clinical observations.
- The financial quality of life subscale score indicates that the informant perceives Very Low QoL for financial aspects of their life due to the child's difficulties, with the score falling below the 0.1 percentile. Please check against other clinical observations.
- The social network quality of life subscale score indicates that the informant perceives Very Low QoL related to their external support network, with the score falling below the 0.1 percentile. Please check against other clinical observations.
- The partner relationship quality of life subscale score indicates that the informant perceives Very Low QoL related to their relationship and interactions with their primary support partner, including consistency of approach related to their child's difficulties, with the score falling below the 0.1 percentile. Please check against other clinical observations.

- The coping quality of life subscale score indicates that the informant perceives Very Low QoL related to their cope with and manage their child's difficulties, with the score falling below the 0.1 percentile. Please check against other clinical observations.
- The change quality of life subscale score indicates Substantially Decreased QoL over the past month across multiple aspects of life satisfaction, with the score falling below the 0.1 percentile. Please check against other clinical observations.

7.2. Interpretation for General Intervention Recommendations

Based on the pattern of scores, the following general recommendations are offered to inform future intervention planning:

- Consider psychosocial interventions to improve the child's ability to engage with and enjoy their social and family environments.
- Consider family therapy to improve family dynamics and cohesion as well as outside supports (both formal and informal) that might improve family functioning.
- Consider individual psychological therapy for the caregiver (dependent on their interest and need), as well as caregiver support resources in the community.
- Assist family in seeking government resources to address financial strain and limitations and/or suggest mechanisms to address current perceived financial strain.
- Recommend local options for improving the family's social network, including community supports such as local support groups, religious-based groups (if appropriate), community activities, and/or access to community and recreation centers.
- If amenable, recommend couples therapy or, if only one parent recognizes the need, individual therapy.
- Consider the full range of individual supports for enhancing coping, including individual therapy, exercise, supportive relationships, or other therapeutic methods for managing stress and improving coping such as exercise, meditation, yoga, etc.
- Identify the domains in which recent quality of life reductions are present, the reasons for recent reductions in quality of life, and recommend appropriate resources for each domain in which the reduction is present.
- Given broad reductions in quality of life, consider a strong multi-faceted intervention strategy that address the child and family situation as well as

external factors which could added or modified to improve overall quality of life.

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