Title: Reliability of the Quality of Life Inventory-Disability (QI-Disability) measure in children with intellectual disability

Running head:
Quality of life in intellectual disability

Authors: Peter Jacoby,[1] Amy Epstein,[1] Rachel Kim,[2] Nada Murphy,[1] Helen Leonard,[1] Katrina Williams,[3] Dinah Reddihough,[4] Andrew Whitehouse,[1] Jenny Downs.[1,5]

1. Telethon Kids Institute, The University of Western Australia, Perth, Western Australia, Australia
2. Department of Sociology, Princeton University, Princeton, New Jersey, USA
3. Department of Developmental Medicine, Royal Children's Hospital, Melbourne, Victoria, Australia
4. Developmental Disability and Rehabilitation Research, Murdoch Children's Research Institute, Melbourne, Victoria, Australia
5. School of Physiotherapy and Exercise Science, Curtin University, Perth, Western Australia, Australia

Address correspondence to:
Jenny Downs, PhD
Telethon Kids Institute
The University of Western Australia
PO Box 855, West Perth, Western Australia 6872, Australia
Email: Jenny.Downs@telethonkids.org.au
Phone: +61411161138

Conflict of interests:
The authors have no potential, perceived or real conflict of interest to report. The study sponsors have had no role in determining any aspects of the study design; the collection, analysis and interpretation of the data; the writing of this paper; or the decision to submit this manuscript for publication.

ABSTRACT

Objective: To assess responsiveness and reproducibility using estimates of test-retest reliability for the Quality of Life Inventory-Disability (QI-Disability), accounting for changes in child health and parental stress.

Method: QI-Disability was administered twice over a one-month period to a sample of 55 primary caregivers of children (aged 5-19) with intellectual disability. Caregivers also reported their child's physical and mental health and completed a four-item Perceived Stress Scale to assess parental stress. Fixed-effects linear regression models examined responsiveness of QI-Disability to reported change in child health and parental stress. Reliability was then assessed using intra-class correlations (ICCs) calculated from QI-Disability scores adjusted for changes in child health and parental stress.

Results: Five of seven unadjusted ICC values indicated at least moderate agreement (>0.70) and two values indicated fair agreement. After accounting for changes in child health and parental stress, adjusted ICC values showed substantial agreement for the total QI-Disability score and four domain scores (adjusted ICC≥0.80). Adjusted ICC scores indicated moderate agreement for the Physical Health domain (adjusted ICC=0.68) and fair agreement for the Positive Emotions domain (adjusted ICC=0.58). Improvements in a child's physical health rating were associated with higher total, Physical Health and Positive Emotion domain scores, while improvements in mental health were associated with higher total and Negative Emotions domain scores indicating better quality of life. Changes in parental stress did not have a statistically significant relationship with QOL.

Conclusion: Satisfactory test-retest reliability was shown. Preliminary evidence indicates that QI-Disability is responsive to changes in child health, but not to differing levels of parental stress.

Keywords: Quality of life; Intellectual disability; Child; Adolescence; Reliability; Test-retest

Abbreviations:

ASD (Autism spectrum disorder)

ICCs (Intra-class correlations)

InterRett (International Rett Syndrome Phenotype Database)

QI-Disability (Quality of Life Inventory-Disability)

QOL (Quality of life)

SD (Standard deviation)

Introduction

Children with intellectual disabilities experience difficulties with the conceptual, social and practical skills necessary for daily living. Some live with physical comorbidities such as epilepsy,[1] recurrent chest infections[2] and sleep disturbances.[3] Mental health co-morbidities are over-represented particularly in those with mild-moderate disability.[4] Some children experience participation restrictions as well as social isolation [5] and each of these factors can adversely affect the child's quality of life (QOL). Parents of children with intellectual disability are at greater risk of experiencing stress and mental health problems than the general population[6,7] In particular, maternal stress can vary in response to challenges, coping and daily achievements.[8] It is therefore possible that the QOL of a child with intellectual disability could vary in response to fluctuations in their physical and mental health as well as primary caregiver stress.

The development of appropriate support mechanisms for children with intellectual disability is an important public health objective. Valid QOL measures that address relevant domains are a prerequisite for evaluating supports that aim to target a person's satisfaction with their life experiences. We have conducted 77 qualitative interviews to identify domains of QOL important to children with intellectual disability, including children with cerebral palsy,[9] Rett syndrome,[10] Down syndrome,[11] and autism spectrum disorder (ASD).[12] These qualitative data were then used to develop items for a parent-reported QOL measure for children with intellectual disability, the Quality of Life Inventory-Disability (QI-Disability).[13] Parent interpretation of items was captured using cognitive interviewing to support content validity.[14] The measure was piloted with 253 parent caregivers and exploratory and confirmatory factor analysis indicated a six-factor structure with items loading onto domains describing "social interaction", negative emotions", leisure and the outdoors", "independence", "physical health" and "positive emotions". Satisfactory convergent validity was demonstrated with internal consistency scores (Cronbach alpha coefficients) ranging from 0.72 to 0.90, composite reliability scores being >0.7, and four of six average variance extracted scores >0.5. Divergent validity was demonstrated with maximum correlated squared scores being of a smaller magnitude than the average variance extracted scores.[13] Initial validation data also provided

satisfactory evidence for known-group validity (for example, children with ASD had lower "social interaction" domain scores compared to children with Rett syndrome). Importantly, validation was similar across different levels of impairment (e.g. if the child could walk or talk), suggesting that QI-Disability could be useful across the spectrum of intellectual disability[13].

Test-retest reliability refers to the stability of the measure over time such that scores are consistent under similar conditions and at different time-points.[15] Reliability is generally less frequently evaluated for QOL measures,[16] although satisfactory test-retest reliability has been reported for some QOL measures including the generic KIDSCREEN measure.[17,18] Evaluative instruments must also be able to detect changes over time when change has occurred, and this is referred to as sensitivity to change or responsiveness.[19] Some QOL instruments have been evaluated for responsiveness to change,[16] a critical characteristic for monitoring in clinical trials and observing individuals over time. Because responsiveness is not well understood in the QOL literature, clarity as to the best methodology for evaluating the responsiveness of QOL instruments is lacking.[20] Several scenarios are possible. For example, measures may be reliable but unresponsive to change; they may exhibit strong responsiveness across administrations but are not reliable; or measures may be responsive but are not valid.[19,21] If a measure is able to validly differentiate individuals whose scores are stable from those whose scores have changed over time, the instrument has provided both reproducible and responsive findings.[19]

QOL is a multi-dimensional construct and we hypothesise that variation in child health and parental stress will be associated with changes in the QOL for children with intellectual disability. This study aimed to assess the responsiveness of the QI-Disability instrument to any such variations over a one-month time frame. In addition, we quantified the reproducibility of the instrument via estimates of test-retest reliability after accounting for changes explained by variation in child health and parental stress.

Methods

Participants

Families who participated in this study had a school-aged child (5-19 years) with intellectual disability, and most had participated previously in research exploring QOL for their child and their family[13] and were registered with one of following databases: Victorian Cerebral Palsy Register,[22] the Western Australian Autism Biological Registry,[23] the Western Australian Autism Register,[24] or the Down Syndrome NOW database.[25] Additional families with a child with Down syndrome had been recruited using network sampling. Families with a child with Rett syndrome were recruited from the International Rett Syndrome Phenotype Database (InterRett).[26] Selected randomly with even distribution across the diagnostic groups, 65 primary caregivers were invited to complete a survey on two occasions separated by one month. The survey was available online, on paper, or could be completed during a telephone interview with a member of the research team with psychology training (AE, NM).

Instruments

Child QOL

QI-Disability is a 32-item parent-report measure evaluating QOL in children with intellectual disability.[13] The questionnaire comprises six domains: Social Interaction (7 items; eg,"Enjoyed the social experiences of mealtimes"), Positive Emotions (4 items; eg, "Showed cheeky or comical mannerisms"), Negative Emotions (7 items; eg, "Been unsettled without any apparent reason"), Physical Health (4 items; eg, "Been alert and aware during the day"), Leisure and the Outdoors (5 items; "Enjoyed spending time outdoors") and Independence (5 items; eg, "Made their own choices for activities or things they enjoy"). Each item is rated on a 5-point Likert scale and parents are instructed to reflect on their observations of their child's well-being and enjoyment of life over the past month. All items are linearly transformed to a scale of 0 to 100, with higher scores representing better QOL. That is, the response "never" was given the value 0, "rarely" was given the value 25, "sometime" was given the value 50, "often" was given the value 75, and the response "very often" was given the value 100. Domain scores are calculated by summing all item scores and dividing that

value by the number of items. The total score is calculated by the sum of domain scores divided by the number of domains.[13]

Child health

Two items regarding child physical and mental health were constructed for this study. Parents were asked to rate over the past month how often their child: (a) had been physically healthy; and (b) had emotional and behavioural difficulties, to indicate mental health. These responses were rated on a 5-point Likert scale ranging from "Never" to "Very Often", and were coded such that higher scores reflected better physical and mental health.

Parental stress

The 4-item version of the Perceived Stress Scale was used.[27] Each item is rated on a 5-point Likert scale ranging from "Never" to "Very Often", and parents are asked to reflect on their thoughts and feelings with respect to their control and confidence over the past month. Two of the items are reverse coded such that higher scores reflect less frequent negative or stressful thoughts. A total score ranging from 0-16 is then calculated by summing across the four items.[27]

Ethics approval for this study was provided by The University of Western Australia Human Research Ethics Committee (RA/4/20/4276) and parent caregivers provided informed consent to participate in the study.

Analyses

We used the method of Bonett[28] to derive a sample size which would give satisfactory precision for our estimates of intra-class correlation (ICC). We calculated that 51 subjects with test and retest data would lead to a 95% confidence interval width of 0.2 for an anticipated ICC value of 0.8. Cronbach alpha values were calculated for each domain. Fixed-effects linear regression models were used to explore the responsiveness of QI-Disability to reported change in indicators of health, behaviour and parental stress. In this approach, the independent variables in the model equations are the health and

stress scores plus a person-specific intercept (the fixed effect) which describes all the between-person variation in dependent variable scores due to unobserved factors. Thus, any time invariant between-person confounding is automatically accounted for, in contrast to the alternative mixed model approach where between-person variation is described using random effects.

Adjustment for child health and parental stress was achieved by applying the following formula, $Y_2' = Y_2 - \beta_p(P_2 - P_1) - \beta_m(M_2 - M_1) - \beta_s(S_2 - S_1)$, where Y_2 is the measured QI-disability score at time 2, Y_2' is the adjusted time 2 score, P_1 and P_2 are the physical health scores at times 1 and 2 , M_1 and M_2 are the mental health scores at times 1 and 2, S_1 and S_2 are the stress scores at times 1 and 2 and the $\{\beta\}$ are the corresponding regression model coefficients. The result of this adjustment is to estimate the Time 2 score which would have been observed had levels of health and stress remained the same. Any residual differences between the scores over time can be attributed to a lack of reproducibility and examined using test-retest reliability methodology. Reliability was assessed using intra-class correlations (ICCs) calculated from the Time 1 and adjusted Time 2 QI-Disability scores. ICCs were interpreted as ≤0.40 slight agreement, 0.41-0.60 fair agreement, 0.61-0.80 moderate agreement, and 0.81-1.00 substantial agreement.[29] We also calculated Minimum Clinically Important Difference (MCID) scores for each QI-disability domain according to the formula MCID = Standard Deviation$*\sqrt{(1-R)}$ where R is the adjusted ICC value.[30]

Results

Sample characteristics

Sixty of 65 (92.3%) invited families were recruited to the study. Fifty-five of these 60 (91.7%) primary caregivers completed the survey on two occasions, separated by a mean (SD) test-retest interval of 35 (6) days. The children were distributed across the four diagnostic groups: 11 with ASD, 13 with cerebral palsy, 16 with Down syndrome, and 15 with Rett syndrome. The median age was 11.5 years old (range 5-19 years), with slightly more than half (n= 31, 56.3%) aged 5-11 years. Twenty-four children (43.6%) were male. The distributions of the QOL, child physical and mental

health, and parental stress data for Time 1, Time 2 and difference in scores, as well as Cronbach alpha values for each domain at Time 1 are shown in Table 1.

Reliability and Fixed Effects

The unstandardized coefficients from the fixed effect models used to correct the ICC values are shown in Table 2. Higher physical and mental health ratings were associated with higher total QI-Disability scores. Higher physical health was also associated with higher Physical Health and Positive Emotion QOL domain scores while higher mental health was associated with higher QOL scores in the Negative Emotions domain, indicating fewer impacts of negative emotions. Parental stress did not have a statistically significant relationship with any of the domains.

Unadjusted ICC values are presented in Table 3 with five of seven values >0.70 indicating at least moderate agreement and two values indicating fair agreement. After accounting for changes in child health and parental stress, ICC values were substantial for the total QI-Disability Score and four domain scores (adjusted ICC≥0.80). Adjusted ICC scores for the Physical Health domain indicated moderate agreement (adjusted ICC=0.68) and for the Positive Emotions domain indicated fair agreement (adjusted ICC=0.58). The minimal clinically important difference for the total score was 4.83 and ranged from 6.40 to 11.21 for the domain scores (Table 3).

Discussion

Using standard test-retest methodology, reliability as measured by ICCs was substantial for one, moderate for four and fair for two of the seven QI-Disability scores. After adjusting for fluctuations in child health and parental stress, adjusted ICC values for all domains improved, and five out of seven domains showed substantial agreement. These findings suggest that, in the absence of changes in a child's physical and mental health, QI-Disability was a stable measure over a one-month period. Our data also suggest that a change of nearly five points in the total QOL score would be a threshold

beyond which important change is documented, data that informs interpretation of whether a change in QOL status could be meaningful.

Whilst mean difference scores for child health and parental stress between the two testing occasions were small, we observed change scores across the available range for each of the indicators. This indeed supports the notion that fluctuations in well-being can occur within relatively short time frames for children with intellectual disability. Our sample included children with Down syndrome, cerebral palsy, Rett syndrome, and ASD, together representing a range of characteristics including severity; impairments such as physical, communication, behaviour and socialization difficulties, and their co-occurrence; medical comorbidities; and different needs for autonomy, as seen in the broader population of children with intellectual disability. In sum, intellectual disability is complex and many children live with the challenges of functional impairments, comorbidities and barriers to achieving strong participation in the community.

QI-Disability scores were responsive to the impacts of changed health status. For example, poor health can be reflected in the greater need for hospitalisation across the spectrum of intellectual disability than for neurotypical children.[31] It is feasible that total QOL, Physical Health and Positive Emotions domain scores would be lower when the child is experiencing poor physical health, and vice versa. It is also feasible that total QOL and Negative Emotions domain scores would be lower when the child is experiencing poorer emotional health and challenging behaviours, and vice versa. On the other hand, QI-Disability responses did not seem to be influenced by changes in parental stress levels. We elected to measure parental stress which we hypothesised would be more variable in response to the daily challenges of the child's complex disability[6] than parental mental health which would be more stable. Our data suggest that parents were able to serve as a consistent proxy for their child's QOL regardless of their perceived level of stress. These findings provide preliminary evidence that QI-Disability is responsive to different contexts for child health but not to differing levels of parental stress.

Test-retest reliability has been reported for the self-report version of KIDSCREEN-27, a QOL measure validated for the general population,[17] following administration to 559 children (aged 8-19 years) on two occasions separated by a two-week interval. ICC values ranged from 0.61 to 0.74 for the different KIDSCREEN dimensions.[17] Test-retest reliability of the short-form KIDSCREEN-10 was analysed also and ICC values of 0.70 and 0.67 were reported for the self- and proxy-report versions respectively.[18] These ICC values suggest moderate agreement for KIDSCREEN-10 as used in the general population. ICC values achieved for the generic QOL measure KIDSCREEN were therefore comparable to the unadjusted values achieved for QI-Disability. Because test-retest reliability requires similar conditions for test administration,[15] we adjusted ICC values by change reported for three indicators (child physical and mental health, parental stress) that could explain a different background state for the period during which QOL was reported, and observed higher ICC values again for the total and each of the domain scores suggesting good reliability overall.

We were encouraged that Cronbach alpha values for our study sample size (n=55) we similar to those found in our original validation sample (n=253),[13] indicating generalisability of the measure to new samples. There were some limitations in our study. For example, we used broad indicators of child health and parental stress that can provide some indication of the child and family situation but cannot provide comprehensive contextual information. This loss of depth may be simplifying our understanding of the responsiveness of QI-Disability. Future analyses could examine how different time intervals could influence estimates of reliability and how additional factors such as the provision of services, new therapeutics or opportunities for community participation could influence the response of QI-Disability to child QOL. We recommend larger studies with longer follow-up periods for additional pragmatic evaluation of the responsiveness of QI-Disability.

In summary, we conducted a single analysis that determined both test-retest reliability and responsiveness to change for the child QOL measure, QI-Disability. We found that QOL scores changed in response to changing health status and by accounting for child health and primary caregiver stress at the time of test administration, we found evidence that QI-Disability was a stable

measure over a one-month period. Our analysis was efficient in providing a person-centred understanding of factors that can influence the reliability of a QOL measure in children with intellectual disability.

Reference List

1.   Robertson J, Hatton C, Emerson E, et al. Prevalence of epilepsy among people with intellectual disabilities: A systematic review. *Seizure* 2015; 29: 46-62.

2.   Sleigh G, Brocklehurst P. Gastrostomy feeding in cerebral palsy: a systematic review. *Arch Dis Child* 2004; 89(6): 534-9.

3.   Surtees ADR, Oliver C, Jones CA, et al. Sleep duration and sleep quality in people with and without intellectual disability: A meta-analysis. *Sleep Medicine Reviews* 2018; 40: 135-50.

4.   Einfeld SL, Ellis LA, Emerson E. Comorbidity of intellectual disability and mental disorder in children and adolescents: A systematic review. *Journal of Intellectual & Developmental Disability* 2011; 36(2): 137-43.

5.   Bigby C. Social inclusion and people with intellectual disability and challenging behaviour: A systematic review. *Journal of Intellectual & Developmental Disability* 2012; 37(4): 360-74.

6.   Miodrag N, Hodapp RM. Chronic stress and health among parents of children with intellectual and developmental disabilities. *Curr Opin Psychiatry* 2010; 23(5): 407-11.

7.   O'Keeffe N, O'Hara J. Mental health needs of parents with intellectual disabilities. *Curr Opin Psychiatry* 2008; 21(5): 463-8.

8.   Folkman S, Lazarus RS. The relationship between coping and emotion: implications for theory and research. *Social Science & Medicine (1982)* 1988; 26(3): 309-17.

9.   Davis E, Reddihough D, Murphy N, et al. Exploring quality of life of children with cerebral palsy and intellectual disability: What are the important domains of life? *Child Care Health Dev* 2017; 43(6): 854-60.

10.   Epstein A, Leonard H, Davis E, et al. Conceptualizing a quality of life framework for girls with Rett syndrome using qualitative methods. *Am J Med Genet A* 2016; 170A: 645-53.

11.   Murphy N, Epstein A, Leonard H, et al. Qualitative analysis of parental observations on quality of life in Australian children with Down syndrome. *Journal of Developmental and Behavioral Pediatrics* 2017; 38(2): 161-8.

12.   Epstein A, Whitehouse A, Williams K, et al. Parent-observed thematic data on quality of life in children with autism spectrum disorder *Autism* 2019; 23(1): 71-80.

13.   Downs J, Jacoby P, Leonard H, et al. Psychometric properties of the Quality of Life Inventory-Disability (QI-Disability) measure. *Quality of Life Research* 2019; 28(3): 783-94.

14.   Epstein A, Williams K, Reddihough D, et al. Content validation of the Quality of Life Inventory-Disability. *Child Care Health Dev* 2019; 45(5): 654-9.

15.   Streiner DL, Norman GR. Heath measurement scales: A practical guide to their development and us. Oxford: Oxford University Press; 1995.

16.   Solans M, Pane S, Estrada MD, et al. Health-related quality of life measurement in children and adolescents: A systematic review of generic and disease-specific instruments. *Value in Health* 2008; 11(4): 742-64.

17.   Ravens-Sieberer U, Auquier P, Erhart M, et al. The KIDSCREEN-27 quality of life measure for children and adolescents: psychometric results from a cross-cultural survey in 13 European countries. *Quality of Life Research* 2007; 16(8): 1347-56.

18.   Ravens-Sieberer U, Erhart M, Rajmil L, et al. Reliability, construct and criterion validity of the KIDSCREEN-10 score: a short measure for children and adolescents' well-being and health-related quality of life. *Quality of Life Research* 2010; 19(10): 1487-500.

19.   Guyatt GH, Deyo RA, Charlson M, et al. Responsiveness and validity in health status measurement: a clarification. *Journal of Clinical Epidemiology* 1989; 42(5): 403-8.

20.   Terwee CB, Dekker FW, Wiersinga WM, et al. On assessing responsiveness of health-related quality of life instruments: guidelines for instrument evaluation. *Quality of Life Research* 2003; 12(4): 349-62.

21.   Guyatt G, Walter S, Norman G. Measuring change over time: assessing the usefulness of evaluative instruments. *Journal of Chronic Diseases* 1987; 40(2): 171-8.

22.   Reid SM, Meehan E, McIntyre S, et al. Temporal trends in cerebral palsy by impairment severity and birth gestation. *Developmental Medicine & Child Neurology* 2016; 58 (Supplement 2)(1469-8749 (Electronic)): 25-35.

23.   Taylor LJ, Maybery MT, Wray J, et al. Brief report: do the nature of communication impairments in autism spectrum disorders relate to the broader autism phenotype in parents? *J Autism Dev Disord* 2013; 43(12): 2984-9.

24.   Glasson EJ, MacDermott S, Dixon G, et al. Management of assessments and diagnoses for children with autism spectrum disorders: The Western Australian model. *Medical Journal of Australia* 2008; 188: 288-91.

25.   Thomas K, Bourke J, Girdler S, et al. Variation over time in medical conditions and health service utilization of children with Down syndrome. *J Pediatr* 2011; 158(2): 194-200.e1.

26.   Louise S, Fyfe S, Bebbington A, et al. InterRett, a model for international data collection in a rare genetic disorder. *Res Autism Spectr Disord* 2009; 3(3).

27.   Cohen S, Janicki-Deverts D, Doyle WJ, et al. Chronic stress, glucocorticoid receptor resistance, inflammation, and disease risk. *Proc Natl Acad Sci U S A* 2012; 109(16): 5995-9.

28.   Bonett DG. Sample size estimates for estimating intraclass correlation with desired precision. *Statistics in Medicine* 2002; 21: 1331-5.

29.   Landis JR, Koch GG. The measurement of observer agreement for categorical data. *Biometrics* 1977; 33(1): 159-74.

30.   Sedaghat AR. Understanding the Minimal Clinically Important Difference (MCID) of patient-reported outcome measures. *Otolaryngology–Head and Neck Surgery* 2019; 161(4): 551-60.

31.   Bebbington A, Glasson E, Bourke J, et al. Hospitalisation rates for children with intellectual disability or autism born in Western Australia 1983-1999: a population-based cohort study. *BMJ Open* 2013; 3(2).

Table 1: Child health, parental stress and quality of life scores at two sample times

Variable	Time 1		Time 2		Difference	
	Mean (SD)	Range	Mean (SD)	Range	Mean (SD)	Range
Child physical health	4.0 (0.9)	1 – 5	4.2 (0.8)	2 – 5	0.2 (0.8)	-1 – 3
Child mental health	3.2 (1.0)	2 – 5	3.5 (1.1)	2 – 5	0.3 (0.7)	-1 – 2
Parental stress	9.3 (3.3)	2 – 15	10.0 (2.6)	5 – 15	0.7 (2.1)	-4 – 7
QI-Disability Domains						
Total	69.8 (10.8)	44.6 – 95.8	70.8 (10.6)	45.4 – 93.8	1.0 (8.1)	-16.8 – 28.9
Physical Health	72.2 (15.9)	37.5 – 100	73.2 (15.3)	37.5 – 100	1.0 (15.5)	-25 – 56.3
Positive Emotions	75.8 (17.3)	37.5 – 100	77.6 (15.3)	50 – 100	1.8 (16.4)	-50 – 50
Negative Emotions	68.0 (14.3)	35.7 – 100	70.4 (13.7)	42.9 – 96.4	2.4 (9.8)	-28.6 – 25
Social Interaction	71.8 (17.8)	17.9 – 100	73.1 (16.7)	28.6 – 100	1.2 (11.6)	-28.6 – 39.3
Leisure	71.5 (16.6)	30 – 100	71.1 (16.0)	30 – 100	-0.5 (10.8)	-25 – 30
Independence	59.4 (23.0)	15 – 100	59.6 (21.8)	10 – 100	0.2 (10.3)	-20 – 25

Cronbach's alpha values from Time 1 scores were as follows: Physical Health 0.68, Positive Emotions 0.90, Negative Emotions 0.77, Social Interaction 0.88, Leisure 0.82 and Independence 0.83, indicating satisfactory convergent validity of the QI-Disability domains for the test-retest sample (N=55).

Table 2: Unstandardized[a] coefficients of regression analysis of child health and parental stress as predictors of QI-Disability scores

Predictor	Outcome (QI-Disability Domain) B [95% CI]						
	Total	Physical Health	Positive Emotions	Negative Emotions	Social Interaction	Leisure	Independence
Unstandardized							
Child Physical Health	3.58 [1.09, 6.03] *p=0.006*	8.53 [3.80, 13.3] *p=0.001*	5.57 [0.04, 11.10] *p=0.048*	-1.64 [-4.80, 1.52] *p=0.301*	3.40 [-0.49, 7.30] *p=0.086*	3.20 [-0.41, 6.81] *p=0.081*	2.40 [-1.06, 5.86] *p=0.167*
Child Mental Health	3.60 [0.97, 6.22] *p=0.008*	3.26 [-1.72, 8.25] *p=0.195*	3.00 [-2.83, 8.84] *p=0.306*	5.43 [2.09, 8.75] *p=0.002*	3.54 [-57, 7.65] *p=0.090*	3.34 [-0.47, 7.15] *p=0.084*	3.00 [-0.65, 6.65] *p=0.105*
Parental Stress	0.22 [-0.70, 1.14] *p=0.639*	0.80 [-0.95, 2.54] *p=0.363*	0.48 [-1.56, 2.53] *p=0.636*	0.69 [-0.78, 1.85] *p=0.242*	-0.08 [-1.52, 1.36] *p=0.911*	-0.86 [-2.19, 0.47] *p=0.201*	0.27 [-1.01, 1.54] *p=0.676*

[a]Unstandardized coefficients represent the mean change in QI-Disability domain score per unit change in health (1-5 scale) or stress (1-16 scale) variable.

Table 3: Intra-class correlations (ICCs) between two administrations of QI-Disability separated by one month, before and after controlling for changes in child health and parental stress, as well as minimal clinically important difference values

QI-Disability Domain	Unadjusted ICC	Adjusted ICC	MCID*
Total	0.71	0.80	4.83
Physical Health	0.51	0.68	8.99
Positive Emotions	0.50	0.58	11.21
Negative Emotions	0.75	0.80	6.40
Social Interaction	0.78	0.80	7.96
Leisure	0.79	0.81	7.24
Independence	0.90	0.91	6.90

* Minimal clinically important difference (MCID) values calculated from adjusted ICCs and Time 1 Standard Deviations[2]