



# Quality of Life and Child Intellectual Disability

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## Introduction

~ Telethon Kids Institute (TKI) is a Perth, Australia-based research organization that strives to improve the health, development, and lives of children and young people through applicable interventions.

~ The Child Disability team uses various methods to explore a vast array of questions related to improving the lives of children with a disability and their families.

~ I worked on a study exploring the determinants of quality of life for children with autism spectrum disorder, cerebral palsy and Down syndrome with intellectual disability, and Rett syndrome.

## Objectives

~ Gain a deeper, statistics-based understanding of the lives of children with intellectual disability, a demographic that I have been passionate about for many years.

~ Learn new quantitative methods of modelling and gain experience working with comprehensive questionnaire data.

## Work Profile

~ First Month: Data Cleaning

~ When I arrived at the beginning of the summer, data collection was just being completed. Thus, for the first half of my internship, I spent my time cleaning the over 400-observation by over 800-variable dataset. This involved coding a number of qualitative response fields by hand and scoring several measures that were included in the questionnaire.

~ Second Month: Exploration and Analysis

~ Throughout the summer, I participated in biweekly team meetings where we discussed progress, emerging patterns, and next steps.

~ I developed models of the relationships between different aspects of a child's life and their quality of life.

~ I also did the statistical analysis for and contributed to the writing of two related projects: the test-retest reliability of the quality of life measure and the predictors of community participation for children with Down syndrome.

## Projects

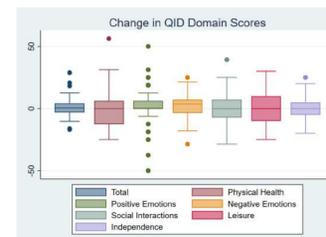
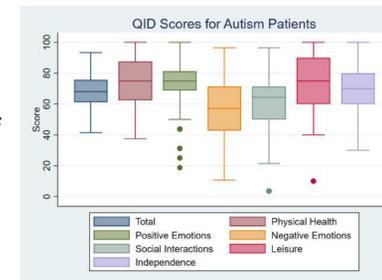
### About QI-Disability<sup>1</sup>

A 32-item parent-report measure, the Quality of Life Inventory - Disability comprises of six domain scores and total score, each normalized to the 0-100 range, that are calculated based on parents' ratings on a 5-point Likert scale of their child's wellbeing and enjoyment of life over the past month. It was created and published by the TKI Child Disability Team in 2019.

### Determinants of Quality of Life

The aim of this study is to identify the modifiable factors that improved or reduce a child's quality of life, both overall and in specific populations. Families were eligible to participate if they had one child between the ages of 5 and 19 with one of the four diagnoses of interest.

Data include information on the child's comorbidities, functioning, participation, etc. and on the family demographics, make-up, and quality of life. I worked with the team to develop models exploring the effects of child functioning and comorbidities as well as maternal physical and mental health on child quality of life. These analyses and more are still being conducted.



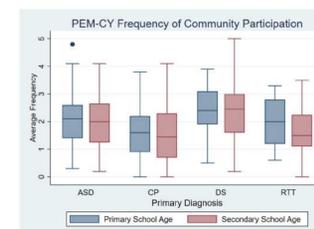
### Test-Retest Reliability

The QI-Disability measure was also administered twice, with one month between administrations, to a subset of families to analyze its reliability. Because these children can experience major changes in the course of a month, the

interclass correlations were controlled for child mental and physical health and parental stress. We found that the QI-Disability measure was stable across time when these factors were accounted for (ICC >0.70). We also found that child mental and physical health were significant predictors of the QI-Disability total score and some domain scores.

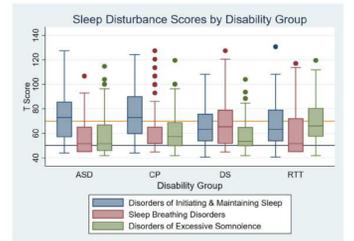
### Participation and Down Syndrome

This small subanalysis found that perceived barriers in the community environment may be important predictors of participation in children with Down syndrome and ID. Family factors and resources, surprisingly, were not predictive.



## Future Implications

~ I became especially interested in the part of the questionnaire related to children's sleep. I am hoping to explore the relationship between sleep and quality of life using this dataset for my thesis. Specifically, I am to determine predictors of healthy sleep as well as the mediation effect of sleep on quality of life.



~ I will continue to consult with Dr. Downs and the team on the determinants of quality of life models. In the near future, I will also be involved in on the editing, revision, and publication of our papers on test-retest reliability and participation in children with Down syndrome.

~ Having engaged with this population of children from a research perspective has only deepened my passion of working with them. I am now considering focusing on child intellectual disability as I pursue a career in medicine.

▲ Above: Range of scores for the Sleep Disturbance Scale for Children, a parent-report measure, separated by diagnostic group, n = 428.

▲ Top: Parent-reported QI-Disability domain scores (possible range: 0-100) for children with autism spectrum disorder, n = 133.

Middle: Changes in parent-reported QI-Disability domain scores from questionnaire administrations separated by one month. Children are evenly distributed across the four diagnostic groups, n = 55.

Bottom: Range of parent-reported frequency of participation scores (measured by the PEM-CY Scale, Community Involvement domain), separated by diagnostic group, n = 428.

## Acknowledgments

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1. Downs, J., Jacoby, P., Leonard, H., Epstein, A., Murphy, N., Davis, E., Reddihough, D., Whitehouse, A. & Williams, K. Psychometric properties of the Quality of Life Inventory-Disability (QI-Disability) measure. Qual Life Res. 2019;28(3):783-794.