

# QI-DISABILITY

## FACT SHEET

### WHAT IS QI-DISABILITY?

Quality of life refers to a person's satisfaction with a composite of their life experiences.

The Quality of Life Inventory-Disability, **QI-Disability**, was developed to specifically assess the quality of life of children and adolescents with intellectual disability (aged 5-18). The instrument was designed by a team of Australian researchers in direct collaboration with the families and carers of individuals across the spectrum of intellectual disability.

Initial qualitative analyses for **QI-Disability** were conducted for children with Down syndrome, Rett syndrome (a severe genetic neurodevelopmental disorder mainly affecting females), and children with cerebral palsy or autism spectrum disorder who also have an intellectual disability. Since its development, studies exploring other diagnoses have utilised **QI-Disability**, including Prader-Willi syndrome (a rare genetic disorder affecting chromosome 15), CDKL5 Deficiency Disorder (a rare X-linked genetic disorder), and other Developmental Epileptic Encephalopathy conditions. Utilising **QI-Disability** for a range of conditions will allow for more comprehensive insight into service utility and intervention targeting the complex needs of this population, with the goal of the child's quality of life as the target.

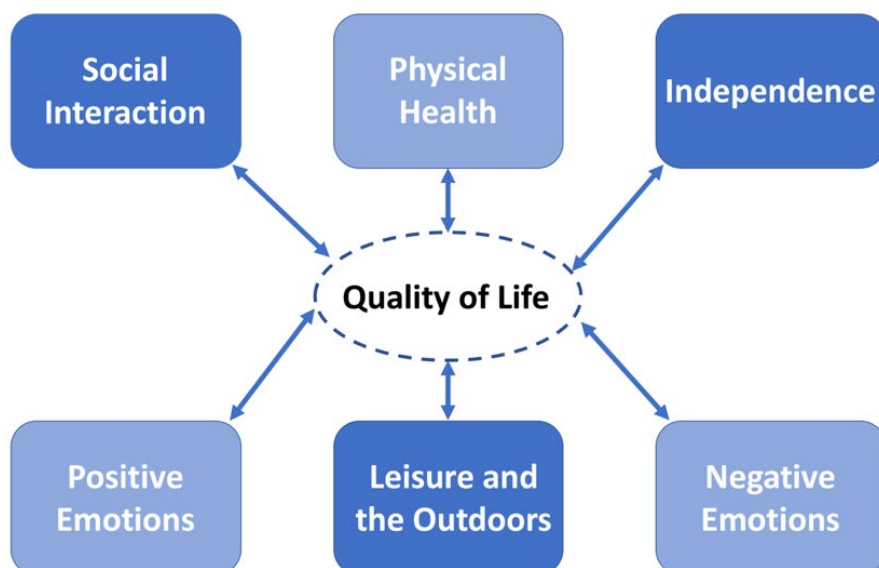
QI-Disability is being used as a monitoring tool in clinic settings and in observational research studies. It is being used as an outcome measure in clinical trials.

### WHAT DOMAINS OF QUALITY OF LIFE DOES QI-DISABILITY MEASURE?

Physical Health  
Social Interaction

Positive Emotions  
Negative Emotions

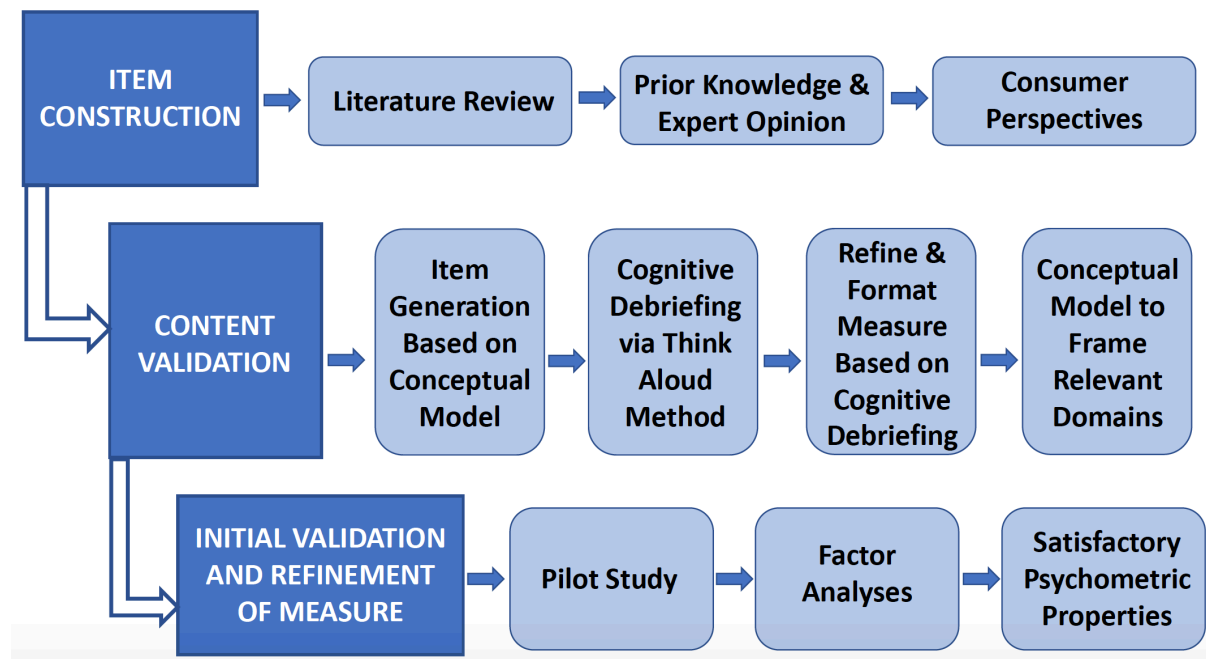
Leisure and the Outdoors  
Independence



## OUR MODEL

**QI-Disability** was developed to address the need for a measure of quality of life constructed specifically for children and adolescents with intellectual disability. The instrument resulted from thematic analyses of 77 primary caregiver interviews, which were conducted to identify the quality of life domains and elements relevant to this population.

The figure below provides a summary of the goals and methodology of each phase of development of **QI-Disability**.



## OUR QUESTIONNAIRE

**QI-Disability** measures children's and adolescents' health and wellbeing across 6 domains. The instrument was developed as a parent-report measure relevant to school-aged children (5-18 years) across the spectrum of intellectual disability severity.

### Administration

**QI-Disability** can be completed by primary caregivers at home, school, clinics or in other contexts. It can also be administered by telephone, in-person interview, using an online platform, or as a paper questionnaire.

When **QI-Disability** is used, the following guidelines are recommended:

- All 32 items comprising **QI-Disability** should be given to the primary caregiver
- All items should be displayed in the same order as written
- All items should retain their exact wording as written
- Likert rating scales should retain the exact wording and order as written

## Translations

**QI-Disability** has been translated into other languages. For more information or if you are interested in performing a new translation of QI-Disability, please contact:

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- Murdoch Children's Research Institute
- Royal Children's Hospital Melbourne
- University of Melbourne

When publishing research study results using **QI-Disability**, please cite the following:

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## Additional information about our research available at:

Telethon Kids Institute: <https://telethonkids.org.au>

The Child Disability Facebook Page: <https://www.facebook.com/ChildDisabilityTelethonKids>

University of Western Australia: <https://www.uwa.edu.au>

Murdoch Children's Research Institute: <https://www.mcri.edu.au>

Royal Children's Hospital Melbourne: <https://www.rch.org.au/>

University of Melbourne: <https://unimelb.edu.au>

## **PUBLICATIONS**

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