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) and CDKL5 Disorder (a rare X-linked genetic disorder). 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.

WHAT DOMAINS OF QUALITY OF LIFE DOES QI-DISABILITY MEASURE?
Physical Health
Social Interaction
Positive Emotions
Negative Emotions
Leisure and the Outdoors
Independence
**OUR PROCESS 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 the following languages:

- Hebrew

The following translations are currently in development:

- Turkish

**Funding and Support**

The development of **QI-Disability** was funded by the National Health and Medical Research Council (NHMRC). This series of studies took place over 6 years (2014-2019), and collaborators included the Telethon Kids Institute Perth, Royal Children’s Hospital Melbourne, and the Murdoch Children’s Research Institute Melbourne.

We would like to acknowledge the following organisations for their support throughout the development of **QI-Disability**:

- National Health and Medical Research Council (NHMRC)
- Telethon Kids Institute
- University of Western Australia
- 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:


**CONTACT US**

If you are interested in using QI-Disability, please contact:

A/Prof Jenny Downs | Principal Research Fellow
Phone: +61 8 6319 1763
Email: Jenny.Downs@telethonkids.org.au

Postal address:

Attn: Dr Jenny Downs
Office of QI-Disability
Telethon Kids Institute
Perth Children’s Hospital
PO Box 855, West Perth, Western Australia, 6872
AUSTRALIA
PUBLICATIONS


